

DOCTORAL THESIS

Understanding the psychosocial impact of exercising with epilepsy: A narrative analysis

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Understanding the psychosocial impact of exercising with epilepsy:

A narrative analysis

by

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A thesis submitted in partial fulfilment of the requirements for the degree of PhD

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Abstract

In recent years, the experiences of sportspeople living with a chronic illness/disorder have seen an emergence within the narrative literature (Smith, 1999; Carless & Sparkes, 2008; Stone, 2009). However, epilepsy has been noticeably absent. As epilepsy and exercise research is mostly quantitative and medico-scientific in nature (Arida, Guimares de Alameida, Cavalheiro, & Scorza, 2013; Dubow & Kelly, 2003; Nakken, 1999; Wong & Wirrell, 2006), there is no qualitative research to show the experiences of sportspeople exercising with epilepsy. Although exercise has shown to be beneficial for most people with epilepsy (Arida, Scorza, & Cavalheiro, 2010; Eriksen, Ellertsen, & Hestad, 2002; Nakken, 1999), research reveals that people with epilepsy often refrain from exercise (Ablah et al., 2009; Nakken, 1999; Sirven, 2009). Furthermore, exercise-induced seizures (EIS) provide a frustration as well as an incentive to refrain from physical activity (Nakken, 1999; Sturm, Berkovic & Reutens, 2002). Therefore, the aim of this research was to provide a glimpse into the narrative experience(s) of a sportsperson/people with epilepsy (SWE) over the course of one year. Using four semi-structured interviews with four participants, differences in experience over time as well as across athletic identity, sport type, and seizure type and frequency were represented. A holistic-content approach and structural analysis were used to analyse the narratives (Carless & Sparkes, 2008; Frank, 1995; Lieblich, Tuval-Mashiach, & Zilber, 1998). Results have shown the importance of time in the narrative construction of the SWE. Presenting a new narrative type, vicious cycle, these narratives also portrayed similar findings as was shown in Lieblich et al. (1998) (e.g., the steady, progressive, and trial and error narrative). The participants expressed a sense of freedom, body control, and mental clarity linked to exercise. These positive benefits encouraged the participants to continue even if hampered by uncontrolled seizures. Furthermore, outside variables (e.g., time, seizure frequency and type, social support, stigma, and athletic identity) have shown to have an affect on the thoughts/ actions of SWE in regards to exercise. Through this research, SWE will have a voice within research. In turn, it is desired that this new insight leads practitioners to develop and implement more effective ways for SWE to cope with the transition of diagnosis.

Abbreviations

ABS- Affect Balance Scale

AED- Anti-epilepsy drug

AIMS- Athletic Identity Measurement Scale

BMI- Body mass index

BPS- British Psychological Society

CES-D- Center for Epidemiological Studies Depression Scale

CFS- Chronic Fatigue Syndrome

CMI- Career Maturity Inventory

CPS- Complex partial seizure

CRS- Control Ratings Scale

EIS- Exercise-induced seizure(s)

IBS- Irritable Bowel Syndrome

IIRS- Illness Intrusiveness Ratings

IPA- Interpretative Phenomenological Analysis

OM-EIS- Objective Measure of Ego Identity Status

PWE-Person/people with epilepsy

QOL- Quality of life

SWE- Sportsperson/people with epilepsy

UK-United Kingdom

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1.0 Introduction

Personal flashback- September 2000: I'm awake. Disoriented, I look down and realise my hands and legs are covered in dirt. That's strange. I start running, but I do not feel so good. I cross the finish line, but still do not feel right. Dad is coming up to me. Oh no, he looks disappointed again. "What happened?" he says. "What do you mean?" "You were winning, Sarah. But when you came around the corner, you were in third?!"

"Really? Well, I think I fell. Look at my hands and legs." Suddenly the pain of the dirt in the grazes on my hands starts to sting. With no memory of how they were created, I wonder what had happened.

It was not until one year later, age 18, that I would understand what had actually happened during that cross-country race. I had a seizure. I have epilepsy. It all made sense now. That black-out, the loss of memory. I had a seizure on the last hill, tripped on a tree branch, froze, and restarted only to get a disappointing third place.

I have loved running since I did my first 'real' run, age 13. The sense of bodily control and the feeling of pushing my body to its limits is such a strong memory, even now, 16 years later. When I ran, I felt that every step I took, I was becoming physically and mentally stronger. This addictive feeling of testing the body and overcoming mental and physical limits was a craving that was satisfied every time I raced or went on my daily run. However, at age 17, strange physical symptoms began to occur, which altered confidence in the strength of my body and mind. Suddenly, at any given moment, I

would black out, lip smack¹ and then vomit. I had no memory of these actions as they occurred; just remembered waking up to a toilet of vomit. Everyone thought it was psychological.

***Self- interview²:** I still remember the day I was diagnosed; it seems burnt forever into my memory. I wondered why my aunt repeatedly took me to a neurological hospital where people around me had carers, were much older than I, and was one of the scariest places to be for someone who had no idea about what was happening to her own body. Once in the doctor's office, he abruptly proceeded to tell me that I had epilepsy. Without a blink, he then continued to discuss epilepsy and the medication I would have to take. However, to be honest, I cannot remember the particulars of what he was saying. All I can remember is his face and me sitting there thinking, "Why is he saying all this stuff about epilepsy? I do not have epilepsy." It slowly occurred to me that maybe I was not listening to him properly, and as we walked down the hall, down the elevator, and then to the car, I just kept thinking, "Do I have epilepsy?" I can still remember, 10 years later, the state of uncertainty of whether I should clarify with my aunt that I did not know if I had epilepsy or not. At the time, I did not fully understand what epilepsy was and I was scared to even ask. There I was sitting with my aunt in the car, driving back to my dorm, and I could not stop thinking, "Maybe I should ask her, but is that a stupid question? Well, let me just ask." So I did. "Aunt D, do I have epilepsy?" "Yeah baby! What did you think?"... "I don't know." I cannot remember*

¹ Automatisms, which are characteristics of complex partial seizures (Barrett & Sachs, 2006)

² Segments of personal reflection completed at the beginning of the research process (see section 4.1)

anymore after that, just the feeling of shock and fear. Even now this memory is so strong. All these feelings, I can still feel now, so vividly within me.

After a period of feeling sorry for myself, I was determined not to let epilepsy negatively affect my running; I could run through anything. Eventually, I would push myself out the door for runs, however, this was horrible. I was so scared of having a seizure while running, that when I had to run by myself, I usually stayed at home instead. This period of pushing through the fear was short-lived. Over time, I realised it was exercise that was the main trigger for my seizures. They arrived like clockwork; twenty minutes into a run - BAM - seizure. I could no longer make it through workouts and felt like a burden on my team³. As a result, I looked for other ways to cope. However, I slowly realised that there were none. It seemed the only answer was to stop running or to continue exercising with seizures. Again, the feeling of being utterly alone and confused set in. Surely there are answers? Others must feel the same? What do they do? How do they feel?

The last couple of years of exercising have been the same: start, stop, start, stop. The constant cycle begins with running, becoming excited about being seizure-free, and then pushing myself to run more. Seizures are the inevitable result, thus creating a negative mental state. Continuing to try to run despite this, on the occurrence of more seizures, I finally give up and stop running until I am brave enough to start again. I have tried to come to terms with this cycle and view my running stature/identity as more

³ I ran track and field and cross country for a Division 1 University in the United States.

recreational, in hope that a non-running day would not upset me as much. I am getting better at coping with this change, but it is difficult sometimes. I want to run and compete too! Why don't I get to? In my quest to cope with this change in running state caused by my diagnosis, I decided to pour my energy and anxiety into finding answers to these questions.

1.1 Where are the stories of others? Am I all alone?

I began this journey by writing an autoethnography on returning to running (Scarfe & Marlow, in progress). The end result was I had to come to terms with the end of my life as an athlete. There are days I can exercise, and then days I physically cannot. I have now realised that there are good days and bad days. Although acceptance is an ongoing issue, would anyone else have a different story to tell? What are their experiences? These questions were constantly running through my mind.

For so long I have desired to hear the voice(s) of another sportsperson/people with epilepsy (SWE). I believe that by providing stories of exercising with epilepsy; doctors, psychologists/psychiatrists, friends, and family of SWE would be much more informed of the psychosocial issues involved. Questions began to stream through my head: what is the outcome of medical professionals prescribing or de-prescribing exercise for their patients? What are the variables involved to successfully exercise with epilepsy? What are the barriers?

1.2 Aims of this research

Ten years post-diagnosis, research representing the exercise experiences of the SWE is still absent within current research. With internet forums being the only source

of storied expressions regarding exercise, I have realised that the absence of epilepsy within sport and health literature will not help others; it needs to be discussed.

Therefore, there are three aims within this research. The first aim is to provide a narrative type of the SWE within current academic/research literature. Within current exercise and health literature, there is a burgeoning trend to examining the narrative type of those with a chronic illness/disorder (Carless & Sparkes, 2008; Frank, 1995). In portraying the SWE's story, I am aiming to provide insight into a chronic disorder that has yet to be presented through narrative means, thus contribute to current research within the area of chronic illness/disorders and exercise. As a result, differences in narrative type can be examined across various illnesses and disorders, thus paving the path in discovering novel ways to exercise successfully with a chronic illness/disorder. In chapter 3, further theoretical and literature background on narrative analysis will be discussed.

The second aim is to provide further insight into specific topics discussed within and absent from current research. Themes to examine within this thesis were derived from current sport and illness/disability as well as general epilepsy quality of life (QOL) literature, in order to assess similarities or differences for a SWE. Drawing from my own experiences with epilepsy, topics for discussion and investigation also became apparent. Although not currently within the literature, it was an aim to examine such topics more closely with the participants to see if such topics held true for the SWE. These topics will be discussed throughout the next two chapters with the intention that it will allow you, the reader, to gain familiarity with themes that may be pertinent within the SWE's narrative of sporting life.

Finally, the third aim of this research is to provide a practical use in the witnessing of the individual's storied expression. SWE should have a voice within current literature, thus making the disorder visible. Providing the SWE's story within research, the end result would finally provide stories within research that other SWE can read, relate to, even show their doctors! This would be beneficial to provide the psychosocial impact of exercising with epilepsy in hopes that future coping mechanisms can be derived.

To assist in the fulfilment of these aims, the following chapter will examine the themes within the exercise, health, and illness/disorder literature more closely. Thereafter, chapter three will address the methodological reasoning for this research, whilst chapter four outlines the research process that was undertaken.

2.0 Understanding epilepsy and exercise

In order to allow the reader to become more familiar with the neurological condition of epilepsy, a brief background defining the disorder, prevalence, and descriptions of seizure types will be addressed below. Thereafter, an in-depth review of the exercising with epilepsy literature and potentially relevant themes, such as identity, body, etc., will be discussed through research within chronic illness/ disorders and health. Lastly, an introduction to the methodological form of the narrative will be presented in terms of its presence within the illness and sport psychology/sociology literature, and thus the contribution this current research can make within that arena.

2.1 What is epilepsy?

Epilepsy is “a chronic condition in which a person has recurrent seizures due to an underlying cerebral process” (Dubow & Kelly, 2003, p.24). A seizure is the occurrence of neurons within the brain discharging excessively and simultaneously (Richard & Reiter, 1995). Epilepsy is diagnosed once one has had two or more unprovoked seizures within two years (Alcaron, Nashef, Cross, Nightingale, & Richardson, 2009), unprovoked being defined as the absence of a separate condition which could produce seizures (Alcaron et al., 2009).

2.2 Seizure type

There are two main classification systems of seizures: generalized or partial (focal) (Richard & Reiter, 1995). Generalized seizures affect the entire brain and body upon onset of the seizure, resulting in impairment of consciousness, with common

generalized seizures being classified as tonic-clonic⁴ and absence⁵ (Barrett & Sachs, 2006). Partial seizures, on the other hand, begin at a focused spot within the brain, usually affecting one sensory or motor system (Barrett & Sachs, 2006). Common partial seizures include complex partial (CPS)⁶, the most common type of partial seizure, and simple partial seizures⁷ (Alcaron et al., 2009; Richard & Reiter, 1995). Consciousness during the seizure varies for partial seizures. Both simple and complex partial seizures can develop secondarily into a tonic seizure (Barrett & Sachs, 2006).

2.3 Incidence and prevalence

As the most common neurological disorder, epilepsy affects 50 per 100,000 people in the UK per year and 50 million people worldwide (Aydemir, Vu Trung, Snape, Baker, & Jacoby, 2009), with 6% of the world's general population likely to have at least one seizure during their lifetime (Jacoby & Baker, 2008). In developing countries, incidence rates are higher than in the developed world, as a huge gap in treatment, stigma of the disease, and lack of antiepileptic drugs create a barrier to care (Aydemir et al., 2009).

⁴ “The individual’s eyes rolling up into the head accompanying a loss of consciousness, and the individual may emit a grunt or piercing cry...the individual will then become rigid, extending the extremities and arching the back (tonic phase), followed by rhythmic contractions of the extremities (clonic phase)” (Barrett & Sachs, 2006, p.94).

⁵ “Brief periods of loss of consciousness without accompanying motor activity. They appear as momentary lapses in attention characterized by staring” (Barrett & Sachs, 2006, p.95).

⁶ CPS can be accompanied by automatisms, which are repetitive actions such as lip smacking, hand movements, facial grimacing, or even undressing (Barrett & Sachs, 2006; Richard & Reiter, 2006).

⁷ Physical or motor symptoms consist of uncontrollable jerking or stiffening in one region of the body. Sensory symptoms often manifest as strange tingling sensations on a part of one’s body, while visual symptoms manifest typically with the occurrence of flashing lights, bright lights, or other visual irregularities (Richard & Reiter, 1995).

Exploring the variances between seizure types, it is of interest to discuss, what is the effect of epilepsy on one's QOL? Furthermore, what role would exercise play with regard to the grading of one's QOL? Prior to discussing epilepsy's affect on exercise life, background on QOL within general epilepsy literature will be discussed to draw attention to epilepsy's intrusiveness in one's everyday life.

2.4 Quality of Life

***Self-interview:** After diagnosis, life seemed to be an ongoing battle of how to live successfully with epilepsy. The pills, the side effects; i.e., weight gain, dizziness, memory loss... I was no longer me, I was a zombie. I miss the old Sarah, happy go lucky, always laughing. I feel epilepsy, or maybe the drugs, has killed that part of me. It's a horrible feeling to not feel like the real YOU. I had bad days and OK days. Some days I would break down and cry, "Why God, Why? What have I done? Why give this to me?" As I get older, now 10 years post-diagnosis, I have begun to accept my epilepsy. However, this has taken years, and I have yet to feel the same acceptance within my exercise life.*

Current epilepsy literature produces a common focus upon QOL for the person/people with epilepsy (PWE)⁸ (Barrett & Sachs, 2006; Dubow & Kelly, 2003; Jacoby & Baker, 2008), however, there has yet to be research exploring QOL for the SWE. One aspect of this research is to focus on how exercise affects QOL for the SWE, therefore, the following section will present general QOL research that is of interest to

⁸ As there has yet to be research published using the term SWE, the term PWE will be used in discussing literature within the epilepsy field, including that within exercise (which will be provided later on in this chapter). SWE will be used in discussion of my current research which has defined a SWE (see methods-chapter four).

this thesis. This will be followed by the exercise and epilepsy topics that can further QOL research within the sporting realm.

Epilepsy is a chronic disorder where one's QOL is affected as uncontrollable seizures interfere with one's daily lifestyle, work, and interests (Poochikian-Sarkissian, Sidani, Wenneberg, & Devins, 2008). Unpredictable seizures, lifestyle restrictions, and unwelcome side effects from anti-epilepsy drugs (AED) are shown to correlate in developing a lower QOL for PWE (Barrett & Sachs, 2006; Poochikian-Sarkissian et al., 2008). Poochikian-Sarkissian et al. (2008) discussed the psychological impact of epilepsy intrusiveness in their QOL study. Using 145 participants, Poochikian-Sarkissian et al. compared groups who varied on seizure control and were being tested for epilepsy surgery. Through the use of the Illness Intrusiveness Ratings Scale (IIRS) (Devins et al., 1983), Control Ratings Scale (CRS) (Devins et al., 1983), Affect Balance Scale (ABS) (Bradburn, 1969), Life Happiness Scale (Atkinson, 1982), Self-Esteem Inventory (Rosenburg, 1965), Quality of Life in Epilepsy Scale (Cramer, Perrine, Devinsky, & Meador, 1998), and the Center for Epidemiologic Studies Depression Scale (CES-D) (Radloff, 1977), multiple measures were examined in relating to QOL. The results of statistical analysis revealed that the perceived intrusiveness of the illness correlated with increased depressive symptoms and a decreased QOL. Also, the frequency of seizures was found to be positively correlated with illness intrusiveness. As seizures became controlled, there was less of an impact compared to the group without seizure control. Poochikian-Sarkissian et al. (2008) therefore suggest a correlation between the frequency of seizures and the resultant intrusiveness on one's everyday life. These results were of interest in the investigation of epilepsy's intrusiveness upon the

SWE's sporting life. Exercise was not discussed within Poochikian-Sarkissian et al., however, this research will be used as a basis for thematic questioning (e.g., intrusiveness of illness) and to see if there was a similar effect regarding exercise and seizures.

Furthering the quantitative findings of illness intrusiveness and seizure frequency, Jacoby and Baker (2008) described the QOL trajectory of PWE. Jacoby and Baker identified that PWE had a poorer level of QOL compared to those without epilepsy. This is particularly evident in: the higher risk of suicide after diagnosis, as well as deaths from accidents or trauma; the higher rates of co-morbid chronic conditions, sleep disturbances, and psychological distress; and the reduced likelihood of being physically active, married or currently employed, for PWE compared to the general public (Beghi & Cornaggia, 2002; Strine et al, 2005).

Upon examining the effects of seizures on everyday life, next to be discussed will be the impact that exercise can have for PWE. Current research explores the effect exercise can have upon creating a healthy lifestyle; both physically and psychologically (Dubow & Kelly, 2003; Roth, Goode, Williams, & Faught, 1994; Sirven, 2009). In examining epilepsy's effect on exercise, this thesis will focus on the effect of seizure control, as well as of how the loss of an exercise routine can impact the SWE's sporting body and mind.

2.5 Epilepsy and exercise

Self-interview: *At University, the black outs continued. I had seizures while running, during workout sessions, and competitions. On one occasion, I walked into the middle of*

traffic while on a run with my team. On another, I fell down as I tripped over branches. This all resulted in my coach fearing for my safety, and thus banning me to run only on the track for the remainder of my time on the team.

I approached my neurologist for answers to my problem with exercising. His answer was to stop running and take up tennis. He obviously did not understand. “Take up tennis? I went to college to run!” I ignored his advice and felt very alone. Fuelled by my anger at his ‘solution,’ I was determined to find answers to my exercising issue and its connection with seizures.

Research has shown physical activity to be beneficial for most PWE because of its positive effects on seizure control and personal well-being (Arida, Scorza, Scorza, & Cavaleiro, 2009; Arida, Viera, & Scorza, 2010; Eriksen, Ellertsen, & Hestad, 2002; Nakken, Bjorholt, Johannessen, Loyning, & Lind, 1990; Wong & Wirrell, 2006). However, there is not a clear consensus within the medical community in regards to the message towards exercising with epilepsy (Eriksen et al., 2002; Sirven, 2009). For PWE, the main reasons for inactivity are the fear of the seizure occurring (Steinhoff, Neuss, Thegeder, & Reimers, 1996), fear of seizure-related injuries (Arida, Cavaleiro, da Silva, & Scorza, 2008; Steinhoff et al., 1996), and being inadequately informed about the possibilities of playing sports (Sirven, 2009). As a result, this inactivity has shown to develop social isolation, low self-esteem, weight gain, and depression (Conant, Morgan, Muzykewicz, Clark, & Thiele, 2008; Nakken, 1999; Sirven, 2009). Furthermore, looking at the effect social support has upon a PWE’s decision to exercise, Ablah et al. (2009) found that 68% of 412 surveyed epilepsy patients were actively discouraged by family members or another influence. As a

consequence of this ongoing hindrance, and despite the specific physical and mental benefits of physical activity, for some, exercise is still not a regular occurrence (Dubow & Kelly, 2003; Sirven, 2009). Continuing within exercise and epilepsy literature, the next section will present further research in the affect of exercise on seizure control as well as issues involved for PWE/SWE in making the decision to exercise.

2.5.1 Role of exercise in seizure control

Examining current research on the benefit of exercise on seizure control provides a basis to explore a more individualized portrayal through qualitative methods. Recent research has looked at exercise as treatment in controlling seizure frequency (Arida, Scorza, da Silva, Schachter, & Cavaleiro, 2010; Arida, Scorza, Scorza et al., 2009; Conant et al., 2008). Within these studies, all have shown that physical activity is beneficial not only to one's self-concept, but by increasing physical health, heightened seizure control occurred as well. As a result of AED effects and inactivity, PWE are found to have higher co-morbid psychological disorders, such as depression and anxiety (Dubow & Kelly, 2003), as well as a higher body mass index (BMI) (Steinhoff et al., 1996). Therefore, moderate exercise has been offered as a possible tool to alleviate such problems (Arida, Scorza, da Silva et al., 2010; Arida, Scorza, Terra et al., 2009; Sirven, 2009). Sirven (2009) urged the increased awareness of the benefits of exercise to PWE because of the development of these co-morbid conditions. Roth et al. (1994) found that positive psychological adjustment, as well as lower levels of depression, were seen in their participants after a moderate exercise regime was instated. Reducing the levels of stress through moderate exercise has also been found to lower the occurrence of seizures, as well as improve mood (Arida, Scorza, da Silva et al., 2010; Dubow & Kelly,

2003; Nakken 1999). These positive effects, both physical and psychological have been effectively shown through research to be a positive motivation for PWE/SWE to exercise.

Investigating exercise habits and frequency in seizure activity relating to exercise, Nakken (1999) had 240 adult participants partake in two surveys. The first survey obtained valuable insight on exercise habits/routines and sport types, while the second examined seizure-related injuries in an exercise setting. Within these results, interesting to discover was that although 10% of participants claimed a connection with increased seizure frequency and exercise, only a small percentage of 2% had been found to experience exercise-induced seizures (EIS), that is “those occurring in connection with exercise (i.e., in >50% of the training sessions)” (Nakken, 1999, p. 645). EIS was found to be most prevalent in those with CPS and triggered by exercise of high intensity, playing ball games, hiking, and jogging (Nakken, 1999). Consequently, as a result of the correlation between CPS and physical exercise, one must ask what psychological effect does this have on individuals, and indeed sportspeople with these types of seizures? There were different reasons reported to why EIS occur, such as stress of activity and hyperventilation, however, Nakken (1999) did not report what psychological effect EIS had upon the participants. Nakken (1999) reported that for PWE with EIS, individualization of exercise regimes was important, as inactivity hinders more than helps the individual with epilepsy.

Looking at specific incidences of PWE who have EIS, Sturm, Fedi, Berkovic, and Reutens (2002) reported two cases of EIS in males aged 16 and 28 years old. Each participant was diagnosed with having left temporal lobe seizures, and seizure

incidences were characterized by occurring within 5-20 minutes of exercise. Although not a qualitative study, this medico-scientific case study provided details of the exercise decisions of the individuals and the advice the doctors provided in regards to exercise routine and/or restrictions. In both cases, exercise was prescribed to be reduced, and in the case of the 16 year old, this advice was followed. After a reduction in his running regime, he became seizure-free for seven months. The other participant, however, was unwilling to modify his exercise habits and he continued to have seizures. This study investigated EIS and what may be a way to calm seizure activity; i.e., modification of exercise habits. Although Sturm et al. (2002) provided examples of participants with EIS, it did not present the reader with the cognitive decision process, nor psychological effect of modifying their exercise habits. Additionally missing from this research was the elaboration upon what classifies as a modification and what were the changes made? Furthermore, in regards to their athletic identity, what was the psychological impact of each athlete's decision on exercise continuance? These questions could be answered in future research within the psychological effects of exercising with epilepsy. Investigating qualitatively, I would further such research through presenting the SWE's story, providing insight into reasoning behind decisions regarding exercise activity, as well as the psychological impact of such decisions or medical recommendations.

2.5.2 Why is exercise not a common occurrence for PWE?

Previously discussing exercise's physical effect on seizure control, this section provides further research into the psychological reasoning behind the lack of exercise within the epilepsy population. Steinhoff et al. (1996) used a mixed-method approach to investigate the physical fitness levels in PWE compared to those without epilepsy.

Steinhoff et al. (1996) combined the use of a semi-quantitative questionnaire designed to assess physical and social activities with physical testing of a 2Km walk, muscle strength exercises, and measure of finger-to-floor distance to measure overall physical fitness. Using differing sample numbers in the two sections, 136 PWE and 145 participants in a normal control group completed the questionnaire section, while 35 PWE and 36 normal controls participated in the physical testing. Results revealed similar statements between the control group and PWE in regards to sports being fun, positive, and suitable for PWE. Comparing the two groups, 42% of the control group exercised regularly, 43% occasionally, and 15% never. However, amongst the PWE, 25% exercised regularly, 44% occasionally, and 31% never exercised. Steinhoff et al. reported that the disorder itself was the main cause for inactivity. With a high percentage of PWE believing sports were dangerous (75%), 41% of the PWE participants reported fear of seizures during exercise, and 40% were worried about sports-related injuries. Following these results, physical and flexibility results showed PWE “had significant deficits in aerobic endurance, muscle strength endurance, and physical flexibility” (1996, p. 1226). Also of significance was the result of a higher BMI and fat ratio in the female PWE participants compared to the control group. Revealing that PWE consider sports to be fun and beneficial to their well-being, these results also provide examples of the high percentage of PWE that are inactive and are not experiencing the effect of exercise for seizure control or physical well-being.

Providing further indications of the psychological and physical barriers of exercise for PWE, Ablah et al. (2009) designed a 4-section survey, using 193 PWE participants, which explored additional barriers to exercise than those previously

published. The instrument examined: one, exercise habits and seizure activity which correlated to exercise; two, addressed psychological and physical barriers to exercise; three, contained questions concerning physical health; and fourth, demographic questions. Results revealed that exercise was common for PWE with 78% reported that they exercise, and 91% agreeing with the statement, “I think of better health and fitness when I exercise” (2009, p.163). However, there were still areas of seizure inhibiting exercise as 15% surveyed participants reported “I think of increased seizures when I think of exercise” (2009, p.163). Twenty percent of the participants also stated that seizures interfered with their ability to exercise. Common barriers seen within these participants were lack of motivation (41%), personal safety concerns (27%), other barriers (26%), fear of seizures (19%), and limited access to facilities (18%). Ablah et al. provide useful themes that could be used as possible topics to investigate within future research. For example, with lack of motivation being identified as a common barrier in PWE, it is important to consider what motivational tools health professionals could use with PWE/SWE to create an easier path towards physical activity? Furthermore, is there a link between fear of seizures and lack of motivation? These are questions that could not be answered within this quantitative study. However, I propose that through the use an open-ended qualitative approach, one can address such questions, providing a more in-depth understanding for future studies and eventually greater knowledge in health professionals and PWE/SWE.

Through examining the present research within the epilepsy and exercise domain, there was shown to be a large gap within current literature amongst the topics previously discussed. The psychological impact of the lack of exercise and/or

motivation for PWE/SWE is missing from the current literature, as is the individual's story on stopping or continuing to exercise. Through looking at previous research involving individuals and sport, it is worthy to consider that there is a psychological influence of identity on such issues. The next section will take a closer look at the concept of identity (e.g., definition of identity, illness and identity, athletic identity, and disabled identity) for the PWE/SWE.

2.6 Identity

***Self-interview:** How do I describe who I am anymore? I am no longer 'a runner,' so what can I call myself? Everyone seems to label themselves in some way, e.g., a mother, athlete, artist, etc. What is my label? I feel like I cannot describe that anymore. I feel confused. I used to be a runner, but now I have epilepsy. I am not epileptic! I hate that word. It makes me feel like that is who I am, and nothing else. It makes me feel incapable. That is not true.*

I remember the day I stopped saying, "I am a runner." As I said the words, "I used to run," I realised, wow, when did that change? Being a runner meant the world to me. Encompassing my whole life, I loved that label. Now, I am in a constant struggle to attain that title once more.

As a concept, identity has differing theoretical constructions on what and how one defines his/herself. Using the theoretical beliefs found within symbolic interactionism, I will be discussing the effect transitions can have upon one's identity, looking specifically at the social, personal, and temporal aspects behind the theory, as well as similarities found within disability and sport identity theory. Symbolic

interactionism, commonly seen within research in disability, health, and/or injury (Allen-Collinson & Hockey, 2007), is based upon the belief that changes in identity depend on one's situation in life. Identity is constantly being re-created as an effect of time, context, and interaction with others (Weiss, 2001). Through our relationships with others, we develop our sense of self, resulting in possible multiple identities within various social spheres (Weiss, 2001). As Goffman (1969) states, it is through the use of props, such as clothing or equipment, that one constructs identity. When a disruption in one's identity occurred, a psychological effect, negative and/or positive was the result (Goffman, 1963). This disruption would be of significance to investigate within epilepsy and sport transition periods. By investigating SWE through such a theory, I am hoping to represent how being diagnosed with epilepsy affects one's sporting life.

2.6.1 The generalized other

Found within identity literature is the concept of the 'generalized other,' which recognises the affect the social group has upon the creation of one's identity. The concept of 'I' and 'Me' interplay as the organisation of one's role is developed through one's social surroundings (Weiss, 2001). This development occurs throughout sporting activities, as well as through being a "conscious member of a community" (Weiss, 2001, p. 399). This concept is of interest to explore using the differing social communities of SWE and sportspeople. Does a SWE feel that they need to belong to one community over another (e.g., disabled vs. sport)? Can they intermix? The development of a strong athletic identity, created by the awareness of society's expectations, could have an impact on the resultant transition to role adaptation for SWE. To further the discussion of identity and SWE, the topic of illness and identity will next be presented.

2.7 Identity and illness/disorders

Research within chronic illness⁹ has provided an inside view of the effect living with a chronic illness can have upon how one identifies oneself (Charmaz, 1994; Charmaz, 1995; Elliott, Lach, & Smith, 2005; Scambler & Hopkins, 1986). Charmaz (1983) described the concept of discrediting as an issue within identity. Charmaz states, “Many suffer discreditation related to their decreased and now marginal participation in the normal world” (p. 181). The next section will examine the topic of discreditation and the concept of identity crisis in having a visible/invisible illness and/or disorder.

2.7.1 Identity and visibility of illness/disorder

Within the arena of chronic illness, research has shown differences between self versus others’ perceptions depending on the visibility of the illness (Charmaz, 1983; Dickson, Knussen, & Flowers, 2008; Goffman, 1963). Visible illnesses have physical limitations that are obvious to the eye where the restrictions may be. With an invisible illness, discrediting occurs by one’s experiences of trying to hide his/her illness or perceived judgement on why he/she may not be taking part in situations when visibly, nothing is wrong (Charmaz, 1983). This discreditation can cause the individual to feel a lesser sense of self/identity. Physical dependency intensified this inadequacy or lessened feeling of identity. This physical dependency can affect both types of illness; visible or invisible. In relation to epilepsy, Charmaz (1983) provided key topics that are of interest to examine within the concept of identity. However, although the topic of discreditation was explored through qualitative research, Charmaz (1983) produced a weakened

⁹ Although illness is used, epilepsy is seen as a condition or neurological disorder (Poochikian-Sarkissian et al., 2008). Within research, chronic illnesses will be used to portray similar findings or themes that run within epilepsy.

emotional understanding of the issues involved because of its lack of in-depth participant output. Through the use of narrative analysis, an in-depth exploration of both invisible and visible illnesses within sport would be advantageous to future research.

Exploring the identity issues for those with Chronic Fatigue Syndrome (CFS), Dickson et al. (2008) described the effect an invisible and contested illness has upon one's identity. Using Interpretative Phenomenological Analysis (IPA), Dickson et al. used in-depth interviews of 14 participants with CFS, which resulted in common themes of identity crisis. Within the illness, many participants reported a feeling of "personal loss characterised by profound diminishing personal control and agency" (p. 463). They go on to describe their illness as dictating their everyday life: "It controls my body and my mind and every part of my being" (p. 463). Many reported feeling useless, numb, and "an empty shell" (p. 464). Showing the differences of a before and after identity crisis, one participant reported, "I felt like part of me had died. I'd have given anything to have it back again. I just wanted to be me. The old me before I got ill" (p.464). The feeling of uselessness and loss of personal control fuelled these issues with the participants. Commonly, the comparisons between their former self and ill-self intensified their identity crisis, a comparison that has also been shown in other illness and/or injury and identity research (Natterlund, Sjoden, & Ahlstrom, 2001; Smith & Sparkes, 2008b), and is an important identity concept found within chronic disorders. For those with invisible conditions, like epilepsy, it would be of interest to examine if similar findings could be discovered for SWE. Through the use of qualitative research, Dickson et al. (2008) provided first-hand accounts of life with CFS. Identity issues arose

as a result of in-depth interviews, and the portrayed excerpts of the participants' interviews allowed the reader to feel they had a greater sense of the impact upon identity change for the person with CFS. This research had a greater amount of participant voice compared to previous research mentioned and, as a result, had a stronger emotional effect. Through using a qualitative design, this thesis will explore the possible identity disruption involved with being diagnosed with epilepsy. This would allow for future research to compare the psychosocial impact across various disorders and the new issues involved when looked at within a sports discipline.

2.7.2 Disabled identity

The concept of a disabled identity is a topic that needs to be discussed, for within epilepsy literature, the belief that one is 'disabled' is of debate between PWE (Rhodes, Small, Ismail, & Wright, 2008). Exploring disabled identity research, Watson (2002) depicted disability through variables that may cause one to feel the disabled identity. Using a qualitative design with 28 participants with visible disabilities (e.g., in wheelchairs, difficulty walking, etc.), Watson revealed that only three of the participants described themselves using the disabled identity. The differences were seen through how he/she challenged the universal view of the self. One participant said, "I don't tend to think of myself as disabled, you know I don't think, oh, I'm in a wheelchair" (p.515). With this depiction, Watson provided examples of individuals that possess a visible disability but do not let it depict who they are. Not being defined by their disability, these individuals have allowed the issue of identification to be a societal projection, compared to how one thought of him/herself. Providing an abundance of participant

excerpts of those with visible illnesses, Watson shared the concept of disabled identity and society's view through the eyes of the participants.

Continuing the self-identification of disability research, using a grounded theory approach, Galvin (2005) provided narratives of how a disabled person identifies him/herself. Although not using epilepsy participants, being disabled herself, Galvin approached the topic as a dialogue between those with an illness sharing their views on how they saw themselves. Discussing the topic of a visible disability, one participant shares, "I kept thinking that (the wheelchair) was all they saw first. They didn't see me" (p.397). The individual was no longer their own identity, but became their disability. As seen in previously mentioned literature, adaptation to life with a disability was key in learning to redefine their identity with a disability. One woman described, "I'd think, 'What's wrong with me?' But now I don't... It took quite a bit of getting used to, but, instead I think, 'What's wrong with them?' Now I never worry about other people's opinions" (2005, p. 399). This research provided further evidence to the topic of adaptation and re-identification with having a disability. The topic of stigma of the disabled label was also introduced, an issue that will be outlined later in this chapter. Galvin provided adequate use of participant dialogue to share the experiences of being labelled disabled. This research provided more first-hand accounts than other research previously mentioned, thus allowing the reader to understand the disabled identity conflict through the use of the participants' own words. Being disabled herself, Galvin would be in a similar situation as myself in regards to interviewing participants. As I will be interviewing SWE, there will be ethical issues involved (discussed further in

chapter four), however, I believe that by being a SWE, this will enhance the quality of the research, as it has done for Galvin (2005).

In examining the topic of disabled identity within the sport and exercise community, it is of interest to see how it is depicted when examining those with an invisible chronic disorder. Would a SWE define him/herself as disabled? This is a question of interest for this research. Prior to discussing sport literature, the next section will examine current research on the topic of epilepsy and disabled identity.

2.7.3 Epilepsy and disabled identity

Self-interview: *Am I disabled? For so long I have struggled with that term. On job applications and demographic requests, I never believed that I qualified under that term. However, as time went on, I realised I am. I need help to get somewhere if I have had a seizure or am feeling 'seizurey.' I cannot drive anymore. I need to take medications to live. All these things made me think, I am not much different than other disabled people. It is just the fact that you cannot see my disability that makes me think I am not. Coming to this conclusion was a hard choice, but it was made and it does not consume me. Yes, I feel not 'normal,' but I'm not. I have epilepsy and because of it, I have lost normality. Living with epilepsy is now my normal.*

As there has been an increase in discussion within research on the disabled label for PWE (Fernandes, de Barros, & Li, 2009; Rhodes, Nocon, Small, & Wright, 2008; Rhodes, Small et al., 2008) and as it is an ongoing personal debate, this seemed to be a key topic to explore within this thesis. As there has yet to be research discussing current

SWE's labelling of disability, the next section will present research involving PWE and the issues involved with the disability label.

Research within epilepsy and identity has revealed the fight between the self and how others perceive him/her (Elliott et al., 2005; Fernandes et al., 2009; Rhodes, Nocon et al., 2008; Rhodes, Small et al., 2008; Troster, 1997). Fernandes et al.'s (2009) research on the affect language can have upon epilepsy identity revealed that language has a high impact. The language of labelling oneself as disabled was not the only identifiable term most commonly refuted by PWE. The term of 'epileptic' has been used interchangeably with PWE, however, recent studies show that this language conveys a label, rather than someone who has been diagnosed with a chronic condition (Fernandes et al., 2009). Such a label produced a stronger stigmatization effect against PWE, thus continuing incorrect perceptions within the community for PWE (Fernandes et al., 2009). This quantitative study revealed how much of an impact language can have upon how the PWE identifies and subsequently copes with having epilepsy.

Rhodes, Small et al.'s (2008) and Rhodes, Nocon et al.'s (2008) research on disability and epilepsy added to the suggestion that through language, one confirmed an identity. Although PWE have rights under the United Kingdom (UK) Disability Discrimination Act 1995, epilepsy "straddles the divide between illness and impairment, disorders of the mind and disorders of the body, spiritual and biomedical paradigms" (Rhodes, Nocon et al., 2008, p.385). As a result, the label of 'disabled' is not always acceptable for PWE (Rhodes, Nocon et al., 2008). In turn, to resist this distinction, many PWE conceal their disorder until it becomes visible through the presence of a seizure (Rhodes, Small et al., 2008). As epilepsy is a hidden disorder, only

becoming visible when a seizure occurs, along with the many forms it can take, it does not fit the 'disabled' concept commonly used within social and academic literature (Rhodes, Nocon et al., 2008). It has been seen that one's own personal biases against the term 'disabled' play on the stigmatization of categorizing oneself within this framework (Rhodes, Small et al., 2008). Similar to earlier research discussed (Charmaz, 1983; Dickson et al., 2008), by keeping invisible, PWE keep from being discredited.

Furthering the research on PWE and the disability label, Rhodes, Small et al. (2008) provided qualitative research of PWE in Northern England, investigating how they identify themselves. Rhodes, Small et al. (2008) discovered that most of the 20 participants felt that using a disabled identity was not acceptable. One participant said, "What really annoys me is that people talk like it's a disability" (p.6). Since the term disabled was regarded as the traditional visible, static impairment, epilepsy was disregarded within that realm. Another participant felt, "I don't think it's a disability to be honest. You probably might not find it with other people, but for me, I don't class it as a disability. I don't think it has stopped me from doing anything" (p. 6). The general classification or interpretation of the word disabled caused many to not think of themselves in this manner. This research was impactful because of the qualitative nature of its research design, which furthered the quantitative previous research on the topic. Presenting individual statements which debated the disability label for the PWE, Rhodes, Small et al. (2008) allowed the reader to gain a sense of the differences in the label of disabled for PWE from a PWE.

Progressing this research into the sporting realm, it would be of interest to investigate whether SWE who identify themselves as athletes identify themselves as

disabled as well. Regarding physical activity and epilepsy, questions that are of interest concerning disabled identity and epilepsy are: do you feel disabled when you can exercise regularly, but occasionally have seizures? Is there a disability determinant which is caused by the number of seizures an individual has? Through using a narrative approach, these questions, amongst others, will be able to be answered by SWE. The next section will define athletic identity and present current research within disability and athletic identity literature. Through examining athletic identity research, both able and disabled-bodied, a fuller contextual background of possible areas to explore within the area of epilepsy and exercise will be shown.

2.8 Athletic identity

Personal flashback- May 2005: It was the track team banquet. Final year of University and we were all getting rewards for being on the team all four years. Recognition for all our hard work. I felt like a fraud. Why was I there? Do I deserve a reward for running by myself on the track? It was a horrible feeling. What do my teammates think? They act all nice, but do they think I deserve this? It made me feel sick inside.

2.8.1 Athletic identity theory

Athletic identity theory stems from the theoretical assumptions behind symbolic interactionism, emphasizing “the relationship between self, society (social structure) and role performance” (Weiss, 2001, p. 396). Adopting certain roles confirms one’s self-identity, and through obtaining society’s approval or disapproval of such role, one feels acknowledged in the chosen role (Weiss, 2001). In sport, unlike other environments, one’s body is seen as an instrument and will consequently affect the chosen role (Weiss,

2001). This latter statement may show to be apparent in SWE as bodies undergo changes once diagnosed (e.g., increased weight with medication side effects, depression, etc.), thus it will be of interest to explore such a topic within the identity role.

2.8.2 Athletic identity literature

Research within the topic of athletic identity delves into showcasing the effect that social, physical, and enjoyment of a sport can have upon how much an individual identifies with their sport or physical activity (Balague, 1999; Stevenson, 2002; Weiss, 2001). Research shows that for those who identify themselves as ‘athletes,’ the individual is committed and emotionally and psychologically attached to their sport (Stevenson, 2002). Investigating athletic identity, Murphy, Petipas, & Brewer (1996) used the Objective Measure of Ego Identity Status (OM-EIS) (Adams, Shea, & Fitch, 1979), Athletic Identity Measurement Scale (AIMS) (Brewer, Van Raalte, & Linder, 1993), and Career Maturity Inventory (CMI) (Crites, 1978) to conduct a quantitative study with 124 intercollegiate American athletes, looking at the effect of a strong athlete identity upon an individual. Results show that those athletes that only identify themselves within the sporting world, will have a more severe loss in identity if prevented from maintaining their sporting life, compared to those who had other focuses (e.g., careers, school, etc.). Using athletic identity research in regards to SWE, it will be of interest to discover if the same holds true within the epilepsy and exercise world.

Although the effects of athletic identity were commonly found in elite athletes (Balague, 1999), Stevenson (2002), however, depicted Masters swimmers, non-elite athletes, as having an athlete identity. Becoming intertwined within the Masters

swimmers' world, Stevenson revealed elements that created an athlete identity for non-elite athletes. Using an ethnographic method, Stevenson revealed stages of identity development that a non-swimmer completed to attain the end result of 'a swimmer.' For example, seeking out an involvement within the sport, and becoming involved with the cultural practices (i.e., terminology, equipment, rules, etc.) within a swimming club. As there was seen to be a formation of an athletic identity, although the individuals were not at elite status, this will be considered when examining the impact of an epilepsy diagnosis upon a SWE's athletic identity.

2.8.3 Athletic identity and injury

Examining injury and sport identity research next, this next section will draw attention to the psychosocial effects of a physical/bodily disruption upon one's athletic identity. As a result of reviewing such research, I am interested in pursuing the possibility of similarities/differences upon one's athletic identity after diagnosis with epilepsy.

Within injury and athletic identity research, qualitative methods have shown to be advantageous to procure a more in-depth analysis of the effects to one's identity post-injury. Allen-Collinson and Hockey's (2007) autoethnographic research used personal diaries for data collection, revealing the effect of an injury upon one's identity. Comparing injury to chronic illness, Allen-Collinson and Hockey stated that there are similarities in how the self is disrupted. To conserve their athletic identity, Allen-Collinson and Hockey revealed physical/bodily appearance was a key element. Upholding their physical state, sleek body, and wearing sports clothes, Allen-Collinson

and Hockey described the effect as, “So whilst at the moment we can’t run or even jog, we still look like distance runners. That helps because I can still see myself in the mirror and not someone else” (2007, p.390). This quote has strong significance in the area of SWE as I question, what happens to one’s identity when they look fit, however, are not able to exercise? With an injury, although one may still look fit, they also might be physically/visibly injured. For example, visible symptoms of icing or taping an injury put into focus that there is something preventing one to exercise. For an athlete with epilepsy, what would be the equivalent? Would it be taking medication? Would it be wearing a medical bracelet? These are questions that would be of interest to discover. Allen-Collinson and Hockey (2007) provided clear qualitative research that opens up their personal and intimate stories to the reader that can only be accessed through their diary entries. Such research is necessary as personal reflection may not always be revealed within an interview. As a result, I am interested to investigate if using a similar diary method as another mode of data collection could provide similar depth to this current thesis.

Following insight into identity issues within the sporting world, current identity and sport research involving the use of the term ‘disabled’ will be next examined.

2.8.4 Disability, sport, and identity

Self-interview: *I put my running gear on and look in the mirror. I see ‘a runner.’*

However, I know the truth. The invisibility of my epilepsy makes me feel like I can be whoever I want to, until I am caught out by a seizure. The effect of not being able to

physically see that I am 'ill' makes me think, 'Well am I?' I do not know. I always feel so confused and not really sure who or what I can label myself as.

Disability and sport are beginning to emerge throughout qualitative literature, with the concept of disabled identity as a thread through much of such research (Brittain, 2004; Smith & Sparkes, 2008a). Identity issues provide insight into the impact of one's disability, exercise routine, and the effect exercise has upon those with a disability. Brittain (2004) provided qualitative, life history research involving 12 Paralympic athletes and their ideas concerning their own identity. One common issue was the feeling that becoming disabled caused social situations to change; there was a difference with how others now saw them. As one participant stated, "A lot of them found it very difficult, obviously to come to terms with it. More so than me. And they found it hard to be around me, friends that I've had for years" (2004, p. 437). Brittain discussed further how society's reactions to an individual's disability affected his/her sport identity. Brittain stated that people's views, "Suggest that physical activity, particularly strenuous physical activity, is not something that people with disabilities are capable of" (2004, p.438). The physical state of the participants' disability had an impact on how they were viewed within the role of athlete. Ranging from others' reactions to parents who hold children back from participating fully within sports, the disabled athletes were not seen as 'true' athletes because physically they had limitations and/or participated in adapted sports. Investigating this theme, it would be of interest to consider if this holds true for SWE, thus providing research on the social effect of an invisible illness and its impact on athletic identity.

Delving into the topic of bodily limits and exercising, Borkoles, Nicholls, Bell, Butterly, and Polman (2008) and Kasser (2009), through the use of phenomenological analysis, provided qualitative research on the exercise experiences of people with multiple sclerosis. Borkoles et al. (2008) discussed that the physical limits to their disorder made exercise an issue. One participant said, “I was a lot more physically active, I used to cycle to work every day. I miss that now, the ability to get on my bike and go out and cycle” (2008, p. 433). Kasser (2009) revealed the motivation to keep exercising as well as the personal feelings the participants had that exercise evoked within them. Participants showed increased self-efficacy through exercise and how it has become a necessity to maintain health, thus portraying the positive effect exercise can have upon an ill body. Unfortunately however, despite using a qualitative structure, Kasser (2009) and Borkoles et al. (2008) lack in-depth analysis of the individual participants. Broken by academic speech, the participants’ narratives were withheld, and future research would benefit in providing a narration format.

Furthering qualitative research on exercising with a chronic illness, Graham, Kremer, and Wheeler (2008) used grounded theory to report identity erosion and renewal for physically chronically ill individuals within an exercise programme. Graham et al. (2008) followed 11 participants and found that many participants felt a sense of loss through their deteriorated physical body and the limits they now possessed. No longer being able to perform the same physical activities as before, some participants felt the striking contrast to their present and past self. One participant states, “From being an outgoing, physical sort of person you were bedridden. That was mind-blowing. Terrible. Shattered. Suddenly this residual bit of fitness I had all my life was going out

the window” (2008, p. 451). For some, exercise allowed many who were no longer able to participate in their same athletic role, to still fulfil the function of that athletic role. Not only did it allow them to revisit part of their past identity, it fulfilled a social role in interacting with others who had a chronic illness: “My energy wasn’t great. I would get into the house and just sit down and say, ‘I can’t be bothered’... I don’t do that now because I think of the exercises... I imagine myself within the group and I do a few exercises at home” (2008, p.450). Some compared their physical status to others, while some also used it as a positive tool to boost their efforts: “I liked competing with people that are more able-bodied than what I am and I sort of say to myself, ‘well, if I can compete against them!’ ” (2008, p.451). Graham et al.’s research displayed the effect that the depletion of exercise upon one’s athletic role can have upon a previous athletic individual. Using a range of illnesses, and instituting an exercise programme, the reader can see the effect first-hand through the participants’ words rather than as a structured summary. This in-depth analysis allows for the reader to discover the importance for the ill body to maintain an athletic status within one’s identity.

As seen from above, studies within chronic illness/disability are documenting the effect and influence of identity upon one’s exercise regime or lack thereof and vice versa. However, focusing on the topic of athletic identity, epilepsy is a disorder that has not yet been researched qualitatively. Epilepsy and exercise is limited to quantitative methodology and research encouraging exercise, but does not allow for the SWE to explain what causes, prevents, or encourages them to exercise and if there is an athletic identity effect. To further provide insight into the topics of interest within epilepsy and

exercise, research on the topic of ‘the body’ and its thematic presence within illness and sport literature will be presented.

2.9 *The body and illness*

Already present in narrative research, the topic of ‘the body’ is one commonly focused on within illness/disorder research (Frank, 1995; Sparkes, 2004; Stone, 2009). Through speaking of one’s personal experiences, one speaks *through* the ill body, evoking a story unfamiliar to us (Frank, 1995). Frank stated that “illness is about learning to live with lost control” (Frank, 1995, p.30). Through this loss of control, one’s human body attempts to either hide the loss as best as possible, or attempt to regain it (Frank, 1995). As the feeling of a loss of control is also commonly seen in people with epilepsy (Jacoby & Baker, 2008), through qualitatively investigating the SWE’s experience, it is of interest to this research to witness this feeling and its effect on their sporting life.

Kleinman (1988) continued the topic of the ill body through discussion of embodiment via symptom descriptions. Through describing an illness, Kleinman proposed that one becomes aware of what the descriptions of illness actually mean in regards to one’s own world, body, and self, and as a result realise the embodiment of others within one’s story. Epilepsy, as a hidden illness, presented itself to be an interesting chronic illness to explore using the concept of sporting and illness body. Previous research suggests that by exploring the concept of hidden illness and epilepsy, concepts such as stigma (Troster, 1998), body self- awareness (Frank, 1995), and identity (Frank, 1995) might have relevance for SWE. As these concepts are symbiotic, it is of interest to this present research to address them in regards to a sporting body.

The concept of the body and its constant changes within an illness is often discussed in relation to identity. Examining research using a longitudinal approach, Charmaz (1995) provided an in-depth look at adapting to life with a chronic illness. Documenting 115 interviews with 55 participants over 5 years to 10 years, Charmaz provided more first-hand accounts over time than within the research already discussed. With a developing illness, the physical changes provide a reality to the illness. One woman described, “I used to have a lot of patience; I could bear anything... But now my body tells me. I can’t control my body” (Charmaz, 1995, p. 664). Comparing the visible to the invisible illness, Charmaz told of one participant’s self-image dilemma, whom with an invisible illness, did not look ill. She stated that people say, “You don’t look like there could be anything wrong” (1995, p. 666). Descriptions of other’s reactions upon one’s illness appearance reveals that with an invisible illness, many mask their illness until they no longer can. This was a way to preserve their unique identity and self-image.

Charmaz (1995) revealed that although there may be bodily changes, there is not necessarily a correlation between change in identity goals and physical decline. Adaptation was the key to maintained identity. It was revealed that perseverance to maintain an identity, as a mother, an employee, or a father caused participants to persevere through bodily limits. For those who did adapt, recognizing limitations or doing an “identity trade-off” (1995, p. 671) was one way of adapting to living with an illness. Charmaz described identity trade-off as: “They feel their losses. They think about their lives. They assess the costs and benefits of relinquishing activities and responsibilities, and therefore, identities” (1995, p. 671). One key path to identity trade-

offs was the integration of self and illness without allowing it to destroy their self-concepts. Through the depiction of the differences between a visible illness and invisible illness, Charmaz (1995) revealed areas of investigation within adaptability and its effect upon identity. This topic is of concern for SWE and has not been discussed within much research, especially within the sport realm. Through examining epilepsy as an invisible illness, it would be of interest to discuss whether similar adaptations are present with the SWE, and resultantly what affect this has on their identity and bodily concept.

As already shown, invisible illnesses have an affect on how one may view the wellness of their physical body. Upon examining the topics involved with invisibility of illness and its possible impact for the SWE, next, the topic of stigma will be addressed through literature in order to examine stigma's effect and importance for the SWE's exercise life.

2.10 Stigma

***Self-interview:** Telling people I had epilepsy did not come as easy as it does presently. Truthfully, it does not even come out that easy now! The change in the person's face from friendly to fearful and uncomfortable is an often occurrence. After a while, I just stopped telling people. Why would they need to know if it was just going to scare them? Within the sporting and academic world, I find it is necessary. Needing help with my academics because of the side effects of my medication as well as memory issues, I could no longer pretend that telling people something was different about me was not to my benefit. I know the safety importance in telling people where I am going to run, or*

even if a running partner did not know that I have epilepsy, that I may have a seizure on a run! Those are never fun conversations. However, the process of discussing my epilepsy with others has lessened my own stigma against the disorder. I have felt that if I do not make a big deal out of it, maybe others would not. This has taken a while to learn, and I still do not tell people who I feel do not need to know.

Defined as “an attribute that is deeply discrediting” (Goffman, 1963, p.13), the concept of stigma is a common topic within epilepsy literature. As the nature of epilepsy is hidden, one can control who or what information concerning the condition he/she imparts, thus ‘discrediting’ his/her image when a seizure physically manifests. Because of the ill fit within disability descriptions, PWE are seen as outcasts as the cause of the illness is unknown to many. The physical manifestations can appear frightening to those who do not know what is occurring, and the lack of awareness of the condition continues to cause PWE to withdraw from social situations for fear of stigmatization (Baker, Brooks, Buck, & Jacoby, 1999; Fernandes, et al., 2009; Rhodes, Nocon et al., 2008; Troster, 1998). Two descriptions of stigmatization have been developed through research; enacted and felt stigma (Scrambler & Hopkins, 1986). Enacted stigma refers to the “discrimination against people with epilepsy on the grounds of their perceived unacceptability or inferiority” (Scrambler & Hopkins, 1986, p.33). Felt stigma, on the other hand, refers to the “fear of enacted stigma, but also encompasses a feeling of shame associated with being epileptic” (Scrambler & Hopkins, 1986, p.33). This may arise from personal comparisons between themselves and the ‘normal’ of society (Jacoby, Gorry, Gamble, & Baker, 2004; Scrambler & Hopkins, 1986).

Through looking at various experiences of the newly diagnosed as well as those who may have had epilepsy for years, I am interested to find the outcomes of how the SWE's social community have approached SWE's attempts at exercising. Have SWE felt stigmatized because of their epilepsy within the sporting realm? What are the occurrences of stigmatization through sports that may differ from everyday life? Through the use of narratives, these questions will be explored. Prior to presenting the purpose of this research, background literature on the use of narratives as a tool for inquiry will be introduced.

2.11 Narrative inquiry

A narrative is defined as “a complex genre that routinely contains a point and characters along with a plot connecting events that unfold sequentially over time and in space to provide an explanation or consequence” (Smith & Sparkes, 2009a, p.2).

Drawing from the recent development to expand methodology from positivistic or realist forms (Smith & Sparkes, 2009a), narrative inquiry has been one method of providing an alternative methodological approach within current research. Through the narrative method, language becomes a tool to provide one's experiences, which may otherwise not be shown. Polkinghorne (1995) describes narratives as the “linguistic form uniquely suited for displaying human existence as situated action” (p.5).

Furthermore, Crossley (2000) acknowledged that language is the tool which makes our experiences meaningful. Discovering the benefits of narrative inquiry, this research will be able to represent linguistically the full experience of the SWE. It will not be limited by quantitative structure and will allow an in-depth ability to represent various elements of exercising with epilepsy.

2.12 Rationale for narrative methodology:

This research focused on the lives of SWE and their exercise experiences. To further this field of knowledge and create awareness of this topic, research needs to extend into qualitative research. To do this, I have chosen a narrative methodology as this will best allow the individual participants to let their voices be heard and provide an in-depth approach to their overall story.

The following section will provide an introduction to current narrative research of chronic illness and exercise, followed by a summary of the purpose for this research.

2.13 Narratives and illness

Within current narrative literature, there is a burgeoning trend to use narratives to discuss disability, illness, and sport (e.g., Carless & Sparkes, 2008; Smith, 1999; Stone, 2009). When one is diagnosed with a chronic illness, there are many ways one perceives and reacts to such news (Aydemir, Tekcan, & Ozkara, 2009; Conant et al., 2008). Therefore, for those interested in the human experience, the narrative methodology deems appropriate to connect with these interpreted experiences (Oliver, 1998).

Insights into the motivations of exercising with multiple sclerosis (Kasser, 2009), barriers to exercise amongst those with diabetes (Lawton, Ahmad, Hanna, Douglas, & Halloweir, 2006), as well as the effect exercise has on one's mood and well-being amongst those who have a chronic disability or illness (Graham et al., 2008), are examples of current literature providing the lived experience of the chronically ill or disabled. As a result, they have promoted the positive benefits exercise can have upon

an ill body. By using narrative analysis, this research will provide a glimpse into the narrative type (Lieblich, Tuval-Mashiach, & Zilber, 1998; Frank, 1995) of a SWE, showcasing the emotional struggles, triumphs, and battles that they partake over the course of one year.

2.14 Purpose of research

Research within epilepsy and exercise has been primarily through quantitative and medico-scientific testing (Arida, Scorza, Scorza et al., 2009; Nakken, 1999; Steinhoff et al., 1996; Wong & Wirrell, 2006). Prevalent themes relevant to this research have already been shown across various streams of literature (Jacoby & Baker, 2008; Nakken, 1999; Rhodes, Nocon et al., 2008; Sirven, 2009; Smith, 1999; Stone, 2009). Through examining this literature, the common missing component is an in-depth look at the SWE. Narratives of everyday life for PWE have been published (Dennison, 2004), however, there is a lack of a focus on exercise. As exercise has been shown to be beneficial for the PWE (Arida, Scorza, da Silva et al., 2010; Arida, Scorza, & Cavaleiro, 2010; Conant et al., 2008; Eriksen et al., 2002; Nakken, 1999; Sirven, 2009), the psychosocial effect of exercise for a SWE is of interest to examine. Using narrative analysis, this thesis will explore the lived experience of the sportsperson once diagnosed with epilepsy. As a result, this research is aiming to present the narrative type of the SWE, provide insight into topics unbeknownst to current literature, and finally, allow access for other SWE to recognise their story within current research.

Documenting individuals of various ages, sporting ability, and seizure type, this research will allow those absent from present quantitative and medical literature to share

their story. As shown in Lieblich et al. (1998), stories “shape and construct the narrator’s personality and reality. The story is one’s identity, a story created, told, revised, and retold throughout life” (p. 7). Based on Frank’s (1995) narrative work and Lieblich et al.’s (1998) narrative theory, I will explore SWE’s narrative type and see how it unfolds over the course of the year. One year of documentation was chosen to provide multiple points at which you, the reader, can see the affect epilepsy has on a SWE’s longitudinal sporting life. By qualitatively documenting the SWE’s life post-diagnosis, concepts of identity (Jacoby & Baker, 2008; Raty, Soderfeldt, Wilde Larsson, 2007; Rhodes, Nocon et al., 2008), social support (Charyton, Elliott, Lu, & Moore, 2009), adaptations to exercise/competition (Arida, Scorza, Terra et al., 2009), and other concepts unknown to present quantitative research, can emerge.

Through this research, SWE will finally break through the mould of quantitative studies and be able to acknowledge their own story as well as other’s around them. In doing this, one hopes the narrative approach will promote an awakening of the psychological, socio-cultural and historical issues within the storyteller’s world. Kleinman (1988) explains that through the telling of one’s story, a healing mechanism can be created in those who express them. The importance of storytelling not only benefits the storyteller, but leads to an awareness of the significance of the “illness meaning” (Kleinman, 1988, p.9) in the applied practitioner and the reader, SWE or not. In turn, one desires that this awareness leads practitioners and researchers to develop more effective ways for SWE to cope with the transition of diagnosis. The following chapter will examine the philosophical underpinnings of narrative inquiry and current narrative literature within illness and sport.

3.0 Narrative as methodology

To explain the philosophical reasoning for choosing a narrative methodology, the following chapter will provide literature which justifies the use of narratives for this thesis. First, the postmodernist position will be introduced to provide a philosophical stance in the use of narrative analysis.

3.1 Postmodernist Position

Within the postmodernism philosophy, there is no ‘right’ method (Richardson, 2000). Richardson (2000) discussed that at the core of postmodernism, no theory, genre, or method can have the universal stamp as the authority of knowledge. Instead, methods are constantly subjected to critique (Richardson, 2000). Within this mode of thinking is the concept of poststructuralism, where language is at the centre, and through its use, one’s subjectivity is shown. However, Richardson (2000) stated this will only be depicted in the fashion of available verbal resources. As a result, in the use of language, multiple discourses from one’s experiences can be expressed to the reader showing that subjectivity can shift and change, it does not remain stable, nor fixed (Richardson, 2000). Exploring the use of language in the storytelling of a SWE, narrative inquiry was deemed the appropriate methodological choice for this research. Using a poststructuralist philosophy, narrative inquiry is emerging as a way of promoting a closeness to a subject matter that cannot be found using quantitative methods (Carless & Sparkes, 2008; Oliver, 1998; Polkinghorne, 1995).

3.2 Narrative as story

In using the term narrative, one can refer to its prosaic or storied representation (Polkinghorne, 1995). Narrative in prosaic text refers to data in the form of natural dialogue or speech (Polkinghorne, 1995). This format refers to the written transcriptions of interviews and field notes, and is coined narrative to describe the collected data which will be used for analysis. On the other hand, narratives as storied representation portray events and actions to be bound together into an organized whole through means of a plot (Polkinghorne, 1995). Although the term story has connotations of make-believe or falsehood, Polkinghorne (1995) goes on to describe not only is the term story able to communicate this form of narrative, but through the use of plot and time, a storied narrative allows the reader to fluidly view the lived experience through the voice of the speaker.

Portraying a storied approach within narratives, Smith and Sparkes (2009a) developed seven basic characteristics that distinguish narrative inquiry from other research. These are:

- Meaning is basic to being human and being human entails construing meaning.
- Meaning is created through narrative, and is a storied effort and achievement.
- We are relational beings, and narratives and meanings are achieved within relationships.
- Narratives are both personal and social.
- Selves and identities are constituted through narratives, and people do and perform storied selves and narrative identities relationally.
- Being human is to live in and through time, and narrative is a primary way of organising our experience of temporality.
- The body is a storyteller, and narratives are embodied (p.3).

Applying these characteristics or principles to narrative research, one can analyse narrative research's affective qualities, for as Oliver (1998) stated, "Narrative analysis is particularly powerful for understanding the fullness and uniqueness of human existence" (p. 247).

Bruner (1986) stated that narratives originated from one of two modes of cognitive functioning, providing multiple avenues of understanding one's stories. One, the 'well-formed argument' is the popular method for scientists. A well-formed argument allows scientists to develop empirical proof in order to find the truth. Secondly, "a good narrative rings true" (Oliver, 1998, p. 248). It does not mean absolute truth, it "convinces by means of lifelike-ness, or verisimilitude" (Bruner, 1986, cited in Oliver, 1998, p. 248). Narratives that have met all key characteristics cause the reader to reflect on their own lives, take action, and nod in agreement (Alvermann, O'Brien, & Dillon, 1996).

Narratives as story are a popular choice to portray the lived experience in present day qualitative literature (Carless & Sparkes, 2008; Douglas & Carless, 2009; Smith & Sparkes, 2009a; 2009b). Within a story, the plot structures the encompassed events and actions into an organised whole (Polkinghorne, 1995). Differing from fiction and large or small tales, storied narratives are "the linguistic form that preserves the complexity of human action with its interrelationship of temporal sequence, human motivation, chance happenings, and changing interpersonal and environmental contexts" (Polkinghorne, 1995, p.7). The following section will examine narrative literature that was reviewed to guide the decision-making process in choosing the narrative analysis method for this thesis.

3.3 Communicating an experience

Describing the narrative as a key component on how we construct, make sense, and relay our experiences, Smith and Sparkes (2009b) focus on how narratives allow people to communicate an experience. Concluding there are two purposes to storytelling, social and individual, Smith and Sparkes encourage the researcher to consider variances between individuals, as well as the use of such structured narratives for societal use. Furthering the idea of narratives as ‘messy,’ they go on to discuss that as human beings are messy, therefore their narrative should be. Narratives allow us to see the “lived experience in all of its variousness, intricacy, and untidiness” (2009b, p. 280). Smith and Sparkes (2009b) encouraged fellow professionals to share the knowledge of narratives as resources to encompass multiple viewpoints and circumstances of sportspeople.

3.3.1 Story analyst vs. Storyteller

Following such encouragement, Smith and Sparkes (2009b) define the difference between story analyst and storyteller. For a story analyst, the findings of narratives are often looked at and examined. The researcher, rather than let the narrative be presented in its raw form, will “employ analytical procedures, strategies, and techniques in order to abstractly scrutinise, explain, and think about its certain features” (2009b, p. 281). The resultant story form is commonly seen as a realist tale (Sparkes, 2002). Argued as neither an incorrect or correct form, a realist tale presents a storied form for people’s voices to be heard in a coherent context, with specific points of their story being addressed (Smith & Sparkes, 2009b).

In the storyteller approach, the resultant analysis is the story (Smith & Sparkes, 2009b). Rather than adding another theoretical element to the individual's story, a storyteller will allow the story to be presented without interpretation. Ellis (2004) stated that a person will employ analytical techniques as he/she tells a story. Therefore, stories, by themselves, can be seen as analytical (Ellis, 2004). Often using dialogue to depict the story, the storyteller differs from the story analyst in the use of creative analytical techniques. These sometimes result in the form of a performance, either theatrical, oral, or visual (Smith & Sparkes, 2009b). After comparing the two styles, it is of interest to this thesis to focus on the role of the story analyst because of my interest in exploring the narrative type for the SWE. Taking on the role of story analyst, I will examine the narratives for thematic undertones, yet create narratives that exhibit a story form. A further discussion of structural analysis will be presented in the methods chapter (see chapter four). The *whats* and *hows* of storytelling will be next shown in order to provide the reader with further theoretical background for narrative analysis.

3.4 The whats and hows of storytelling

Sparkes and Partington's (2003) research on narrative psychology explored the ideals that "people structure experience through stories and that a person is essentially a story-telling animal" (p.293). In order to this experience, a focus on the *whats* and *hows* of storytelling is a key component seen within present narrative literature (Carless & Sparkes, 2008; Holstein & Gubrium, 2000; Smith & Sparkes, 2009a, 2009b). Important to distinguish between the two, the *whats* of storytelling focus more on the content of what was said, compared to the *hows*, which asks questions as to why a story was told in a particular manner (Sparkes & Partington, 2003). An example of this distinction within

narrative research was shown within Sparkes and Smith (2002), which focused on the whats of storytelling for men and spinal cord injury within sport. These results were able to attain core themes/topics, which depicted this specialized population. This is compared with Frank (1995), who interviewed people with cancer to organize and view how they constructed their illness story. Using such a guide, it is of interest to this thesis to initially find both the whats and hows of a SWE's story. Breaking into a new area of research, these stories will be viewed for content, and from there be examined for the narrative type of their story. Next will be a discussion on the hows of narrative analysis, as I have previously discussed the potential whats in chapter two.

3.5 Narrative decomposition

In depicting narratives as stories, certain literary tools are used to present the end result. The following will be a discussion of such tools, including differing levels of narrative analysis and the use of language and voice within narratives. This will be followed by the use of time as a tool to structure and present narratives to the reader.

Although within postmodernism there is no right method, breaking down the elements within a narrative has progressed narrative analysis to examine how language is used within current research. Using the philosophy behind poststructuralism, there has been a surge in the use of narratives to depict the lived experience (Smith & Sparkes, 2009a, 2009b). Providing research with language at the centre, current literature has begun to breakdown the formation of narratives, creating levels and elements to a 'good' story (Crossley, 2000; 2002; Hyden, 1997; Murray, 2000). To examine such elements, the following sections will provide research describing such elements and what

encompasses a ‘good’ narrative, thus examining the aspects that contribute to create the hows of narrative analysis.

3.5.1 Narrative levels

Exploring the topic of levels within narratives, Murray (2000) presented how a good narrative integrates multiple aspects of the storyteller’s personal, cultural, and social world within a narrative. The following describes the various narrative levels of personal, interpersonal, ideological, positional, and finally, the result of integrating the levels within a narrative type.

First, the personal level is depicted as connected to the phenomenological approach. A narrative is viewed as an organization of how one perceives a situation as well as a helpful tool in becoming more aware of oneself (Murray, 2000). Therefore, narratives become a tool to bring order to a situation that can be seen as chaotic or mute (Murray, 2000). Due to this personal level, narratives can be seen to provide a therapeutic function; as Frank (1995) believes, at the heart of an illness narrative lies the epiphany. It is through these narratives that the individual will make sense of their world, allowing for identity reconstruction. Commonly seen within illness narratives (Charmaz, 1983; Frank, 1995; Williams, 1984), a narrative focused on the personal level allows the individual to be discussed within not only their personal world, but within a social context as well.

Second, the interpersonal level draws attention to the interview process as an important key to understanding an individual’s narrative (Murray, 2000). This was shown through Mishler (1986), which promoted the use of integrating the interview

within the participant's final written narrative. Mishler believed that one would need to consider the interviewer's questions, conversation context, as well as reviewing whether different questions provided multiple types of narratives. As seen by Mishler (1986), research questions asked during an interview are pertinent to the creation of a narrative. In accordance with this philosophy, as researcher and interviewer, the choice of questions within each interview, as well as how comfortable the participants were with my research style, was significant to the creation of the narratives. It is through acknowledgment of the importance of the interview process that the interpersonal level was achieved within this PhD research.

Third, Murray (2000) next described positional level, which draws attention to the influence of the interviewer's social characteristics upon the narrative end result. Within illness narratives, Radley and Billig (1996) discussed the effect that the interviewer's health status could have upon the participant. For example, a healthy young woman interviewing elderly and sick women caused the participants to feel as if they were complaining and found it difficult to express fully how they felt (Murray, 2000). Using this as an example, it is hoped that I, as a SWE, will be able to negate some of these effects. It may be seen that as someone with the same condition as the participants, going through a similar situation, a more detailed depiction of their experience can be described. It can also be argued that because researcher and participant both have epilepsy, the participant may not discuss everything out of assumption that the researcher knows already. However, being aware of that factor, multiple reflexive and interview techniques were put into place for prior, during, and

post interview in order to lessen this occurrence. These techniques will be discussed further in the following chapter.

Finally, within Murray's (2000) ideological level, it is intended that the phenomena that it is discussed within a narrative will provide a social construction of a never before shown experience. Farmer (1994) describes how the interaction between experience and narrative allows for social representations to form: "Narratives thus provide a means of exploring how constructions of the concrete are grounded in culture, as well as how individual experience transforms and participates in the creation of shared knowledge" (p. 432). It is through the use of the ideological level that this thesis hopes to achieve a similar result. As the SWE story has yet to be told, one goal is to provide an individual's experience in order to share knowledge and possibly form new social representations.

Murray (2000) discussed the integration of the levels to form the most poignant of narratives. Through integrating the levels, this thesis is aiming to provide impactful SWE narratives for the reader and SWE alike. Moving from the depiction of levels within narratives, the types of illness narratives will now be described. This will be followed by an explanation of the importance of narrative tools as seen within current research.

3.5.2 Types of Illness Narratives

Hyden (1997) discussed three types of illness narratives: illness as narrative, narrative about illness, and narrative as illness. This depiction of different types of illness narratives will be examined to demonstrate how exercising with epilepsy will be

presented within this thesis. First, illness as narrative is described as “the illness is expressed and articulated in and through a narrative” (1997, p. 54). This is a narrative which combines the use of narrative structure to portray the illness and its resultant effect upon the individual. For example, how did the participant explain their illness? Did they feel it was a hopeful story? Or, do they portray their story as a never ending decline within the illness? This is similar to narrative type, as seen in Frank (1995). Second, narrative about illness serves primarily as a way for doctors and other professionals to discuss an illness. This allows for a conveying of knowledge and ideas about a patient’s experience; for example, a case-study approach that examines an illness. Third, narrative as illness allows for a narrative or insufficient narrative to portray the illness. For example, a patient who does not have the means to articulate his/her experience, however, through his/her story one understands the illness more efficiently. This can be viewed through memory lapses within the narratives, speech difficulties, and other variances to portray the illness through the narrative. Within epilepsy and exercise literature, narrative about illness is dominant. Therefore, using Hyden (1997) as a guide, I am interested in portraying both the illness as narrative and narrative as illness. Portraying the hows of the SWE narrative, it is through the participants’ own words, pauses, and forgetful moments, that their illness will be voiced with the aim of furthering medical and personal knowledge about the SWE.

3.5.3 Narrative elements

Furthering the depiction of the hows of narrative analysis, the following will provide literature on narrative tools (e.g., language, voice, and time), to achieve a more

impactful narrative for the reader (Charmaz, 2002; Crossley, 2000; Mishler, 1986; Sparkes & Partington, 2003; Tsang, 2000).

Crossley (2000) drew attention to the importance of language as a key role in the construction of the self and one's identity. She stated that is through talking and writing, "that individuals are constantly engaged in the process of creating themselves" (p.10). Furthering this belief, Crossley (2000) believed that for narratives, one must attempt to preserve the essence of the individual and how their use of language or discourse form how the individual views and understands their world. It is of interest to this thesis to acknowledge language within a narrative, especially when verbal talking may be hindered or problematic because of medication side effects for some participants.

The topic of 'voice' is seen within narrative research as an essential tool to the storied effect of narratives (Charmaz 2002; Hyden, 1997; Tsang, 2003). Providing a voice to the participants, as well as voice to the researcher is a decision for a narrative researcher (Frank, 2000; Mishler, 1986). How do you as a researcher want to portray the participant's voice? This is one question that began and has remained central to this narrative analysis process.

Using voice as a tool to tell her stories, Tsang (2000) used a narrative approach to explain her experiences of identity within high performance sport. Tsang introduced different methods of portraying her identity through narration and different speakers throughout her narratives. Switching from academic voice to narrator, Tsang portrays the importance of voice as a tool to pull the reader in and help create a fuller picture of her story. Through this portrayal, she hoped to engage the reader and evoke a response.

As a result of the narrative forms presented, Tsang provided an example of how voice and engaging stories can be beneficial in the presentation of the topic of identity.

Hyden (1997) continued on from Tsang (2000) in the discussion of the importance of voice, stating, “the patient’s speech acts as a voice that was strong enough to stand up against the voice of medicine” (p. 49). Providing unique access to an illness, individual narratives allow outsiders to gain access to the individual’s illness experience. In using one’s voice as a tool for narrative creation, I am also hoping to engage readers and allow a personal reaction to occur through the reading of the individuals’ world through their eyes. In addition to voice, Hyden (1997) depicted the importance of time within the narrative framework, furthering the draw towards using a temporal context within a narrative.

Crossley (2002) explored the topic of temporality within narratives, drawing attention to Carr’s (1986) work which used a phenomenological approach to show how an individual experienced and depicted time. Carr (1986) believed human experience was configured by the past-present-and future. Using Husserl’s theory of time consciousness, Carr described how this holds force within narrative formation as we consult our past experience, imagine the future and view the present as the link between the two (1986). Carr goes on to say, “the narrative grasp of the storyteller is not a leap beyond time, but a way of being in time” (1986, p.89).

Explaining that biographical time was shown to be important within life story research, Sparkes and Smith (2003) focused on the effect time has on structuring a narrative. Discussing that throughout their research on men with spinal cord injuries

within sport, biographical time affected the illness narrative, particularly as there was shown to be a before and after injury identity. Comparing how time was spent and taken for granted prior to injury, and then post-injury becoming a dictator for their life, they became embodied by time and body limitations, resulting in an effect on the resultant narrative structure. Viewing these ideals of time as significant to the narrative verbal construction, it is of importance to this thesis to take into consideration the effect of time within each SWE's experience. Is time a strong factor for the evolution or stagnation of the SWE's story? As experiences with epilepsy can change over time (Scarfe & Marlow, in progress), this research will not ignore the participant's past experiences, for as seen from above, the past forms part of one's present narrative. For example, previous sporting experience prior to being diagnosed may have a profound effect on the current narrative. This research will draw on aspects of this topic, furthering research within illness narratives.

Looking at elements that may be present within the illness narrative, it is therefore of interest to this thesis to not only explore what occurs for the SWE, but how the telling of a narrative and importance of time may evolve for the SWE's narrative over one year. Does time and voice (i.e., silences, etc.) play an essential part? Does it make a difference that I, as researcher, have epilepsy too when they are discussing personal issues? These are questions to reflect on and discover over the course of these narratives. Upon reaching a decision on how best to portray a narrative, the particular narrative analysis technique was chosen after careful consideration of the variances within narrative research. As I am interested in analysing the psychosocial relationship between exercise and the SWE, I began to explore other literature within sport and

illness/disorders in order to find a research method that presented narratives in a similar way to how I desired to portray the SWE. Next, the present variances of narrative analysis within sport and illness research that were examined prior to the choosing of the analysis tool for this thesis will be discussed.

3.6 Which narrative analysis to choose?

Deciding on narratives as the most effective way to display the SWE's story, the research process began with examining which narrative analytical methods to use. Through examining different narrative types of performance, body, life history, and illness narratives, the shape of the participants' words through narrative analysis was discovered.

First, examining the approach of restorying narrative analysis, Ollerenshaw and Creswell (2002) explained their approach to creating narratives. Dissecting raw data into plot elements, Ollerenshaw and Creswell depict an approach that urges the importance of time as a tool for the construction of a narrative. Presenting a narrative that is a re-telling of events via thematic analysis, Ollerenshaw and Creswell's approach takes away the presence of the participant's own words as central. Resultant narratives read as stories from a book, with a central narrator (in this case-researcher) being separated from the story. Negating the participants' own words was not how I desired to depict SWE's narratives. However using the common concepts of time and restructuring, I was intrigued in how I might bring forth some of these ideas into my own narrative analysis.

Exploring further, Smith and Sparkes (2008a) described the efficient use of narrative analysis for disability studies. Furthering the depiction between story analyst

and story teller, Smith and Sparkes describe the use of structural analysis within disability research to be rare. The strengths of a structural analysis drew attention to “how narrative material might be used to learn about the development of plot line and variations in structure” (Smith & Sparkes, 2008a). Although there are benefits to a structural analysis, Smith and Sparkes also acknowledged the weaknesses of such an analytical tool. One set-back to this method was that through the awareness of ‘types’ of narratives, individuals may then be categorized in one or the other. As a result, there can be a loss of the individual’s experiences.

Looking at men with serious mental illness in a sport and exercise setting, Carless and Douglas (2008) used Lieblich et al.’s (1998) categorical-content analysis narrative technique. This created categories and major themes within each narrative, compared to an overall structural narrative. Finding major story types throughout the 11 participants’ stories, Carless and Douglas provided a narrative in which main themes are shown for the reader. Within this style of narrative method, one can find key themes that run parallel across the participants; however, it is also of interest to see how the participants are telling their story. Do the participants see their story as positive? Hopeful? As a process? These are the questions that are of interest to this thesis. Within Carless and Douglas (2008), the process over time allowed the individuals’ story to shift and shape, and therefore led to an interest in examining the SWE’s narrative holistically. Although the holistic investigation sparked excitement in using this narrative technique, I, however, differed in the view that the narratives should be segmented by the authors’ clarifications and theory, thus breaking the flow of the participants’ narrative. This led me to continue the search in the narrative analysis method.

Performance narrative was next explored as it may have ‘fit’ the exploration of sportspeople and their sport. One example of performance narrative that was of interest was Douglas and Carless (2009). The theoretical approach was similar to this thesis’s interests, and I found myself drawn into the narratives. Exploring themes across participants, Douglas and Carless (2009) used Lieblich et al.’s (1998) narrative analysis technique and adapted it for the athlete. Interested in the holistic-content approach, however, the resultant narratives were not as ‘storied’ as hoped. Interrupted by their academic introductions and explanations of segments of narrative, the result effect was a desire for a more storied narrative presentation.

The aforementioned narrative analysis examples led to Carless and Sparkes’s (2008) narrative work of mentally ill men and their physical activity experiences. Using the narrative analysis of Lieblich et al. (1998), Carless and Sparkes’s final narratives present the participants’ words to the reader in a narrative form that created a sense that he/she is hearing the story from the participants’ own lips compared to a re-telling via the researcher. Using a content analysis approach, themes were drawn from the interviews, and a resultant mental map was created. Creating charts and visual representation of each participant’s data allowed for a more manageable representation of each participant’s experience (Carless & Sparkes, 2008). The second phase involved a creative non-fictional depiction of the participants’ stories. This resulted in unbroken narratives of the participants, using segments from the interviews thematically pieced into a coherent story. The goal of this thesis for depicting participants’ experiences in their own words was achieved via this method within Carless and Sparkes (2008). Therefore, I knew that there was precedent to depict the narrative appearance that was

desired to be achieved for this thesis. Further explanation and steps in regards to the analytical method will be described in the following chapter.

3.7 Concluding thoughts

Drawing from these current trends in narrative and illness within sport, there is a consistency in aiming to depict the individual story. The narrative theory based on Lieblich et al. (1998) has been used in much of present day sports and illness narrative literature, and as a result, to keep consistent, this method will be used within this research. Although there is a growth in narrative depiction, there is also a variance in style. Using the same theory, the previously discussed research differed in the depiction of the participants' voices, some drawing a more in-depth narrative than within others. To further current day research on epilepsy and exercise, I have chosen to present these narratives in a similar structure to Carless and Sparkes (2008).

This chapter drew upon a background of research within illness narratives as well as the methodological limitations in current narrative research. Comparing research within other illnesses to that within the epilepsy field, there is a gap which, through using a narrative technique, this thesis hopes to fill. As now the philosophical justifications for choosing the narrative method for this thesis have been stated, the next chapter will present the narrative analysis method used. Upon discussing the narrative method, an introduction to the participants involved with this research will be shown to associate the reader prior to reading each narrative.

4.0 Method

Through the use of narrative analysis, personal narratives have been introduced as a popular way to provide meaning to an experience (Davis, 2006; Smith, 1999; Smith & Sparkes, 2009a; Ward, 2008). As shown in chapter two, narrative analysis is seen as a way to discover the human experience of living with an illness/disorder. Therefore, as I am interested in the human experience, the narrative methodology was deemed appropriate to connect with these interpreted experiences (Oliver, 1998). In this chapter, the research process performed for this research will be described and justified.

4.1 Reflection

Reflection is an important methodological process within qualitative research, allowing for preconceptions to be acknowledged (Etherington, 2004). As researcher, and a SWE, I needed to keep my own thoughts concerning the emotions and memories that may be stirred from the conversations with the participants within my control. In order to limit the affect of the nature of my interviewing style or the compilation of the stories, multiple reflective steps were taken. These were implemented to be able to recognise any potential limitations and/or benefits to this research due to personal entanglement. The following discusses the steps involved, including a self-interview and the use of constant reflection throughout the research process.

4.1.1 Self-Interview

Prior to commencing interviews, I conducted a self-interview (Langdrige, 2007). Through this process I reflected on any pre-conceptions that were possessed such as; reactions to diagnosis, emotional response to lack of physical activity, and

living with seizures. By performing a self-interview, I took steps to become aware of any personal emotions or ties to sway the interview and analysis process. The purpose of this self-reflexivity is not to become objective, but to increase my “awareness of the interpretive vision that might be adopted and imposed on research participants during the interview or the subsequent analysis of interview transcripts” (Ryba, 2008, p.342). In addition, through writing and talking about my own experiences within epilepsy and sport, I was able to put myself through a similar emotional and psychological journey that was proposed for the participant. As a result, I became more aware of the potential difficulty of discussing the topic of epilepsy and exercise. The excerpts from this initial self-interview appear within this thesis to allow the reader to become more aware of the personal reasoning behind performing this research, as well as to promote myself as accountable for my research decisions. The process of self-reflection continued throughout the research process.

4.1.2 Reflect, Reflect, Reflect

Memo writing (Willig, 2008) and maintaining a reflection journal (Kvale & Brinkmann, 2009) provided an ongoing resource for my own need to tell my story as I heard others’. Reflexivity was performed through writing in the journal prior to and after interviews, as well as through constant discussions with my supervisors. As was discussed in regards to the self-interview, excerpts from this reflection journal are also shown throughout this thesis under the title ‘reflection journal’. Not only did reflection create an increased self-awareness of my affect upon the research and vice versa, but it also served as a tool to improve the analysis technique and writing throughout the thesis. Discussion on how this was achieved will be discussed at appropriate junctures within

this chapter. In keeping reflection constant throughout the research process, the goal was to establish trustworthiness and maintain reflectivity (Kvale & Brinkmann, 2009).

The reflection process began prior to each interview, with self-reflection of my current emotional state and of any pre-conceptions held about the upcoming interview. Through this process, I was able to see potential emotive responses that may occur through the interview, and then take preventative steps by discussing such issues with a supervisor. Upon completion of each interview, reflective notes would be taken immediately on what occurred visually with the participant's body, voice, facial expressions, and emotional reactions as well as if there any questions/clarifications of topics for future interviews. Not allowing time to diminish my memory of the participants, immediate reflective notes created a way for each interview experience to be witnessed, adding to the narrative experience. These notes were used as a memory boosting tool during narrative analysis. Within this immediate reflection, notes were also taken on how I felt during the interview, as well as other topics that seemed of importance, e.g., themes raised, interview technique, etc. Documenting my own feelings and thoughts, therefore, added to my interview technique as well as revealed any self-issues that may disturb the eventual narrative results.

Here is an example of a post-interview immediate reflection:

Reflection journal- 13/9/11: I just had my second interview with Gwen... I'm very pleased with the interviewing so far. It seems like a nice flow of conversation. She seems relaxed and comfortable, which is what matters.

Reflection continued during the transcription process. As I transcribed, I took further notes on questions that could be asked for the next interview, themes that were emerging within the interviews, the affect the interviews had upon my own mental state, and critique of my interview style to improve for next time.

Here is an example of reflection whilst transcribing:

***Reflection journal- 16/9/11:** Gwen's interview touched on a lot of hot topics within me, such as telling people when, how, and how frustrating it is to not be able to train for anything. I've said those exact words, so it was hard not to cut her off. But, I thought I did well, and made sure I controlled myself. These interviews do touch nerves though, and I feel as though I want to tell someone that I feel like that too.*

During analysis, reflection continued on how the narratives were shaping and any personal frustrations or reactions with the analysis method that was felt at the time. As the reflection process for this research was very important in maintaining a trustworthy data collection, I will next discuss the steps and issues presented in attaining ethical approval.

4.2 Ethical Approval

Ethical approval was sought and approved by the University Ethics Board prior to recruiting the participants. The following provides the ethical issues involved within conducting and analysing this research, along with the solutions to these ethical concerns.

4.2.1 Ethical Issues

Prior to ethical approval, a thorough investigation of the issues that would arise through the interview and research process was performed (Etherington, 2004). The issues that seemed most pertinent in regards to the ethics of this research were: one, participant and my own (researcher) safety during the interview process; two, the sensitive subject matter discussed during and post interviews, and the psychological effect this may have upon the participants and myself; three, the desire for the participants to view this research as therapy rather than research, with me as a therapist; and four, through using a concurrent research design, I may have an effect upon the participants' exercise life. Viewing these concerns, various solutions were put into place to appease the ethics board, supervisors, my own concerns, and the possible concerns of the participants. These solutions to create an ethical and safe atmosphere for the participants and myself are presented in the following sections.

4.2.1.1 Interview safety

Participants' seizure type, physical manifestations, and triggers were discussed prior to interviewing to make interviewing a safe process. Safety precautions were taken into consideration regarding interviewing in private homes. However, this was not needed as all interviews took place in public places (discussed later within this chapter). The location and time of the interview, as well as when I had arrived and left the participant, was always known to my supervisor or a close friend. As a safety precaution, my mobile phone was switched on and remained with me throughout the interview. First aid safety was of importance, particularly if the participants or I had a seizure during the interview. I am a certified Red Cross first aid administer, thus have

been trained in seizure safety and in the differences in seizure physical manifestations. As a result, I was aware of the safety actions one must do for every seizure type, and would have been able to react to any such medical situation. To reduce the risk of prolonged seizures, I made sure the participants had been taking their medicine through prior conversations via telephone and/or email. In addition, I asked participants to alert me prior to our scheduled interview if they had a recent seizure or felt too unwell to be interviewed on a scheduled day. Two interviews were postponed and rescheduled: one, because of a participant had a seizure earlier in the day; and the second, as I had experienced a seizure on the planned interview day. Regarding the issue of my own seizure safety, I discussed my seizures and their physical manifestations with my participants prior to interviewing. I am under medication, but as I have CPS, if I had happened to have a seizure, I would have not needed medical attention. No seizures took place throughout the interviews.

4.2.1.2 Sensitive subject matter

As intimate and sensitive topics would be discussed, it was stated upon the consent form (see appendix 1), and within earlier non-recorded conversations with each participant, of the possibility that the participants could become emotional or be emotionally affected by topics brought up within each interview. To help ease this concern, participants' anonymity, through the use of pseudonyms, was preserved. It was also discussed prior to interviewing and written on the consent form, that participants would not have to discuss anything they did not wish to. At any moment during the interviews, the participants were allowed to stop the proceedings and were allowed to leave the research without repercussions. Participants were told they may withdraw from

the study through the use of their pseudonyms. Although the participant may withdraw from the research, it was clearly stated to the participants that their completed data may still be used or published. Information was provided to accessible support groups through Epilepsy Action UK and emotional, informational, and listening support through the UK epilepsy helpline. Additional psychological services were offered through British Psychological Society (BPS) chartered psychologists. These were stated on the consent form to provide any participants extended help or discussed more in-depth had I felt they may be a harm to themselves or others. In keeping with BPS guidelines, confidentiality would have been broken in this latter case as was clearly stated in the consent form.

As researcher, and a SWE, I needed to keep my own thoughts concerning the emotions and memories that may be stirred from the conversations with the participants within my control. This was to limit the affect upon my interviewing style and/or the compilation of the narratives. This was achieved through the reflection process that was previously discussed in section 4.1.

4.2.1.3 Researcher, not a therapist

Through prior discussions with the participants, I clarified the distinction between researcher and therapist; that this was a research study and I am not a certified therapist. With one of my participants, Andrew (pseudonym), I had to state this again as his initial email and phone exchanges seemed to signify that he wanted advice. It was made clear that advice would not be provided, however, he was alerted again to the

outside referrals that he may find useful. This clarification seemed to calm him and as seen within his narratives (chapter 11), he made use of these referrals.

4.2.1.4 My influence over the outcome

The statement addressed by the ethics board that, through using a concurrent research design, I may influence the recovery process, was a valid concern. However, as I am interested in examining how one learns to live and exercise with epilepsy, a concurrent design was decided as the most appropriate method. This was compared to a retrospective perspective which would create further limitations in regards to the dependence on memory. Through the use of multiple data collection methods, i.e., interviews and diaries, it was hoped that an increased depth in the amount of resultant research would emerge.

In deciding to research a population of which I am a part, I understand I will need to respond to issues of participant-researcher effect. How will I prevent myself from becoming emotionally moved? How will I create a study that is not all about me? Through the process of reflecting (shown in the section 4.1) on how I could affect the study, I chose steps to reduce such effects. I understand that I will have an affect. However, my intention is to ensure that the positives of my personal engagement outweigh the negative. Would participants open up in the same way to someone who did not have epilepsy? Would I be able to ask the same questions had I not been in the same or similar position? I believe my strength within this research is the fact that I have epilepsy. If I did not, I would not want to do this research. Because I am affected, this research has taken place. Similar personal entanglement was seen in Galvin (2005) and

was shown to have a positive influence on data collection in the production on in-depth and exclusive access to information unbeknownst to current literature. Following ethical approval, recruitment of the participants began. Next, the recruitment process will be presented.

4.3 Recruitment

For this research, four participants were involved in the interview process over the course of one year. Discovering that the data had amounted to at least 400 pages of transcription, and after discussion with supervisors, it was felt that keeping the number to four participants allowed for a more in-depth narrative result. The first three participants were recruited through the Epilepsy Action UK research database within England. The fourth participant was recruited via an epilepsy centre in Southern England. Participants were recruited from various regions across England, ranging from Yorkshire, to the outskirts of London. The criteria for participants were: 1) epilepsy was seen as the main condition, not a secondary condition (Santiago & Coyle, 2004); 2) they were 18 years of age and older; and 3) that participants should exercise or play sport at least three times a week, or would like to do so, were they not hampered by their epilepsy. The criteria were set to ensure that sport was important to the participant, as well as an epilepsy diagnosis (Dubow & Kelly, 2003). To allow for future research to be derived from the possible differences in sporting levels, varying levels of sport participation were labelled: recreational, club/regional, national/elite; however this was of no consequence to recruitment. Seizure type and sport type were also of no consequence to recruitment, but as stated previously, each was documented to portray variances across seizure types for possible future research.

4.4 Interview Process

Over the course of one year, four interviews, one every 3 to 4 months, were undertaken with each participant. Following recruitment, the first interview was conducted as soon as possible. The interviews were semi-structured/conversational in order to get into a ‘conversation’ with the SWE (Dale, 1996). In the use of narrative analysis, it is of interest to this thesis to portray what this particular experience of exercising with epilepsy means to each SWE. This was achieved by focusing on questions of what and how, and not why (Nesti, 2004; Smith & Sparkes, 2009b). Within the first interview, each began with a generic opening question of: “Describe your experiences of exercising with epilepsy?” Background questions were asked concerning exercise routine, family life, work, and basic demographic questions. The interview guide (see appendix 2) was developed from themes within the current sport and exercise, and sport and disability literature, as well as from topics of interest within epilepsy and exercise that were not seen within current literature (as considered in Chapter 2). All questions for the subsequent interviews were based on questions that were developed through reflection whilst transcribing, general follow-up questions, as well as other themes that needed to be explored more in-depth, e.g., sport importance, identity and sport, epilepsy diagnosis, epilepsy and its effect on sporting life, etc.

The desire for the researcher/participant relationship was that it should be one based on trust and rapport. This was initially built through early conversations via email and/or telephone, as well as from general chatting prior to recording of the interview. As sensitive material was discussed, it was important that the participants felt comfortable with me as a researcher desiring to learn more about their experience with epilepsy. As

they were willing to share their experiences, I was willing, where appropriate, to share mine as well, in order to gain a sense of trust and build rapport with the participants (Galvin, 2005).

After providing information on the aim of this as research and not a means of psychological support (discussed earlier in section 4.2.1.2), each participant signed and was given a copy of the consent form, allowing for the interview to be recorded and their words used as data within publications. Interviews began only after written and verbal consent from each participant was obtained. All interviews took place at a location that was comfortable for the participant (Borkoles et al., 2008; Galvin, 2005; Irvine, Davidson, Hoy, & Lowe-Strong, 2009). Depending on the convenience for the participants as well as their ease of travel, we would arrange to meet in hotel lobbies, coffee shops, and/or an interview room at the University of Roehampton. Interviews varied in length depending on the participant, lasting approximately an hour and a half, to four hours. Along with the four interviews, personal diaries were supplied to the participants. The next section will discuss this process and reasoning more in-depth.

4.5 Diaries

Individual diaries were provided for participants to capture their thoughts and to add depth to their lived experience (Dornelas, 2008). Diaries were used as a memory-boosting mechanism for interviews, as participants were asked to discuss any activity that caused them to reflect on their sporting life. This served as a way to portray any vivid events that might be helpful in drawing the picture of their sporting life and body (Willig, 2008). Many epilepsy drugs have side effects which create cognitive slowing,

memory loss, as well as reduced verbal fluency (Alcaron et al., 2009). Through the use of diaries, the participants may be able to communicate emotions or situations which they find difficult to express verbally because of the side effects of medication. In using a diary, it was hoped that the participants would view it as another tool to communicate as well as to track occurrences more accurately. Diaries have been found to create an initial painful or negative emotion as they may be evoking an experience that would not be as easy to discuss (Grinyer, 2004). However, after time, writing has also been found to have a therapeutic effect (Dornelas, 2008; Smith, 1999). Although this was not advertised as a benefit of participation in this research, it was of interest to discover if such possible outcomes could occur as a result of diary writing for use in future research.. The participants were told that the diaries were not mandatory and were another tool for them to communicate their exercise experiences whilst in-between interviews. Each participant provided formal written and verbal consent prior to accepting the diaries. Diaries were kept by the participant, and although permission was granted to use their diaries as additional data, no diaries were collected. Two participants, Gwen and Maya decided that they would rather read excerpts during interviews, than hand over the full diaries. These excerpts are seen within their narratives (see chapters 5 and 7). The other two participants did not read aloud from their diary. Results found in the use of diaries will be discussed within the conclusion. After data was collected, narrative formation by narrative analysis was performed.

4.6 Narrative Analysis

Shaping the narratives through the position of story analyst (Smith & Sparkes, 2009b), a holistic-content approach and a structural analysis were used to analyse the

narratives (Carless & Sparkes, 2008; Frank 1995; Lieblich et al., 1998; Smith & Sparkes, 2009b). As outlined in chapter three, a holistic-content approach views the complete “story as a whole, contextualized in a culture and history, and attempt to grasp the overall pattern or guiding metaphors” (Bleakley, 2005, p.537). Further structural analysis focused on the way the participant’s narrative was organised (Smith & Sparkes, 2009b). Using diachronic data, or data that relates to temporal patterns or events (Oliver, 1998), structural analysis allowed for the stories to show distinct features of structure in which a narrative type is formed (Smith & Sparkes, 2008b). As shown in Lieblich et al. (1998), stories “shape and construct the narrator’s personality and reality. The story is one’s identity, a story created told, revised, and retold throughout life” (p. 7). Based on Frank’s (1995) and Lieblich et al.’s (1998) narrative research, I explored SWE’s narrative type and saw how it unfolded over the course of the year.

4.6.1 Narrative Structure

The following describes the narrative types that were used as reference in finding whether the participants’ final analysis fit a narrative type. These narrative types were used as I am interested to discover whether findings for a SWE will be similar to current illness research. Although I was interested in discovering if there were similarities between the SWE’s narrative type and current research, I was also open to exploring possible new narrative types that emerged from analysis.

Frank (1995) described three types of narratives: chaos, quest, and restitution. Within chaos narratives, an individual cannot see a way out of his/her misery, nor a hope for the future. The restitution narrative, on the other hand, has the expectation of

returning back to health. In the restitution narrative, one follows the plot of, “yesterday I was healthy, today I’m sick, but tomorrow I’ll be healthy again” (p. 77). The final narrative shared by Frank is the quest narrative. Described as a “hero’s journey” (p.116), a quest narrative depicts the illness experience as an awakening, a purpose, a journey that starts with an illness and allows them to come to a new sense of self-reflection unknown to oneself before.

Lieblich et al. (1998) presented narrative structures¹⁰ as a result of narrative analysis. Within their research, different narrative structures were a result of investigations over time. Examples of such narratives were the steady, trial and error, progressive, and decline narrative. Lieblich et al. drew attention to the factors involved with shifts in one’s narrative and the patterns that develop in these structures. Exploring narrative type was of interest for the SWE, and would be used for investigating similarities compared to current illness literature.

Currently, there is no present research on analysing the narrative type of the SWE, but as seen in research with chronic illness (Carless & Douglas, 2008; Frank, 1995; Zilber, Tuval-Mashiach, & Lieblich, 2008), multiple types can appear within an illness narrative. By using narrative analysis, this research aims to show the narrative type of a SWE, showcasing the emotional struggles, triumphs, and battles that they partake over the course of one year.

¹⁰ Structure and type will be used interchangeably (Carless & Sparkes, 2008).

4.6.2 Narrative method

Using current literature as a basis (Carless & Sparkes, 2008; Frank, 1995; Lieblich et al., 1998; Smith & Sparkes, 2008a; 2008b; 2009a; 2009b), a step-by-step analysis method was developed for each narrative. In desiring to hear the voices of each participant, the end result was the creation of narratives in which I am visually and verbally absent. However, as researcher I had a major role to play. My voice may not be seen, but I am present in the decisions to focus on various themes, as well as shape the narratives in this fashion (Carless & Sparkes, 2008).

In order to provide the lived experience for the reader, the narratives were developed from the transcripts and diaries of the participants (Langdridge, 2007; Ryba, 2008). After each interview transcription, narrative analysis was performed. This process began with thematic coding using colour coding, as well as the marking of themes in the margins of each transcript. Once this initial method was finished, the transcript was re-read to make sure there were no other themes present (Lieblich et al., 1998).

Using a creative non-fiction analytical technique (Carless & Sparkes, 2008), each narrative was analysed using an overall view of the present themes, and shaped to convey the participant's overall story to the reader. Each narrative is presented using this technique and follows the chronological sequence of the interview timeline. These results will be discussed within the discussion section (Chapter 13). Being interested in holistic-content, the technique of creating each narrative proved more difficult than first thought. Once coding was performed, each theme was written on a separate paper and

then organised into general, overall themes. Examples of the theme titles include: exercise and epilepsy, seizure effects/triggers, social support, etc. Once each theme was sub-divided, these were then ordered with regard to importance to the story and overall interest within the thesis. For example, if one participant spoke of her issues with driving the most, this would be a noted theme, however, I would not use all this material as it was not exercise relevant (i.e., if it did not pertain to her inability to get to a exercise venue, etc.). As a result, although one topic might have had a great deal of importance to the participant, it may not be discussed in great detail within the narrative because of its irrelevance to this current thesis. This was a hard process as I felt that I was betraying my participants for not allowing everything they discussed to be kept present. However, as a researcher, I also realised that there needed to be limits and if it was not relevant, the overall aim of this research was the guide to regulating topics.

Upon documenting the relevant theme order, a thematic map was created (Carless & Sparkes, 2008) similar to a mind map (see Appendix 3), allowing me to visually see connections and be more aware of the data in front of me. As a result, I was able to gain a greater sense of each narrative and how they were unfolding. This allowed visual changes over time to be achieved. For example, in later interviews, new themes developed and thematic connections began to intertwine whereas in earlier interviews, there were no such connections.

After the thematic map was created, structural analysis began. This involved segmenting the transcript into each theme, and then placing them in regards to their importance to the overall story, as well as fluidity in reading. Creating the narratives was

completed multiple times until I felt comfortable with how smoothly the narrative read and of the appearance of theme importance to the reader.

Reflection journal- 16/5/11: I am finding piecing together the phrases quite difficult. Do they flow smoothly? Will the reader understand why exercise is not the first topic discussed? Do the flow and snippets draw an accurate picture of Rose? Am I putting too much in? Leaving too much out?

Following the completion of all the narratives, the last step was conducted again, to ensure that the relevance to the overall narrative was apparent, whilst topics that did not address the research questions were further edited. An interesting result were the changes in each story over time and the difference in amount of information that was derived in later stages compared to earlier interviews. Some narratives stayed a similar length, while others grew, or became more compact.

Developing a narrative through narrative analysis, one must remember that the researcher's story also contributes to the make-up of the narrative and how the participants' stories are interpreted (Alvermann et al., 1996). Knowing that I will play a key part in each participant's story as researcher, I acknowledge that my role has influenced the data formation. Although these narratives will be shaped according to my interpretation of the data, the participants themselves have input to the narrative's creation. Member-checking (Borkoles et al., 2008; Irvine et al., 2009), where the narratives were presented back to the participants to ensure an appropriate proper portrayal of their story, was conducted to promote trustworthiness. Participants were provided with a copy of their narratives after the first stages of analysis. Each participant

responded back and provided written feedback. Two participants expressed a sense of embarrassment of how they appear to have constant mood swings, but the overall consensus from all four participants was that their narratives portrayed their story correctly. Allowing them to read over their own stories and challenge any disagreement or misinterpretations was key to the shaping of each participant's story. This assured me that these narratives were an appropriate representation of their experience. Post-member-checking, subsequent analysis occurred to 'tighten up' each narrative. This involved re-reading for clarity and making each narrative more succinct. Upon analysis completion, each narrative's structure and thematic analysis were examined for relevance to current literature (Arida, Scorza, Scorza et al., 2009; Arida, Scorza, da Silva, et al., 2010; Arida, Guimares de Almeida, Cavalleiro, & Scorza, 2013; Baker, 2002; Carless & Douglas, 2007; Eriksen et al., 2002; Frank, 1995; Lieblich et al., 1998; Nakken, 1999; Rhodes, Nocon et al., 2008; Rhodes, Small et al., 2008; Sirven, 2009; Smith & Sparkes, 2008b; Stevenson, 2002; Sturm et al., 2002; Weiss, 2001).

In regards to narrative creation, I differed to previous literature (Carless & Douglas, 2008; Frank, 1995; Smith & Sparkes, 2008b) in the desire to physically separate the structured final narratives by the interview questions. Questions, instead, were integrated into the narratives to provide context for the reader. Narrative formation in this style has been seen in current research (Carless & Sparkes, 2008), and allowed for the narratives to read as if it was only participant speech. The aim in providing narratives that have little to no academic interruptions was to tell the participants' story without outside context (i.e., researcher comments), thus creating a more storied representation. The next section will present reflections on the narrative process,

drawing attention to problems, concerns, and joys in the use of narrative analysis.

Literature used to help create the narratives will be then be discussed in regards to how it was used in the research process.

4.7 Narrative formation reflection

As the reflection process was integral to this narrative method, interwoven within this section are reflexive notes that were part of the reflection journal that was kept throughout the research process. Documenting the struggles of using narrative analysis to the decision-making process of editing the narratives, next, the reflections on using narrative analysis for this thesis will be shown.

4.7.1. Structuring issues

Reflection journal- 18/5/11: As I am developing my narrative for Rose, I find it difficult to be confident in my initial placement of themes. Does this run smoothly? Does this even make sense? I am enjoying seeing the pieces fit together, but am nervous that I'm leaving things out. Is this the best possible configuration of her narratives?

Creating each narrative proved to be a harder task than first imagined. Throughout the analysis process, doubts and uncertainty were shown to be a drawback of using narrative analysis. I was constantly worried and this was not a desirable feeling as I finished this thesis. Basing the analysis process on the previous narrative literature mentioned (see chapter 3), I still struggled to see if I was properly portraying each participant's story. Having had such long and interesting talks with each participant, editing and extracting topics that they felt were important was harder than I thought.

***Reflection journal- 20/9/11:** I'm currently analysing Maya's first interview. It's a bit difficult putting it together and making it run smoothly. Should I re-word things for clarity? Do I need to add a few words so the reader understands the next jump in flow of thought? I don't want to add too much, so am thinking I will just keep it to her words with my additions from my questions in parentheses. Then the reader may hopefully understand.*

Fighting my way through the multitude of themes presented by the participants, I felt I was drowning within the immense amount of data collected. At times, I had to take steps back to re-adjust themes, to add more themes, as well as detract themes that were not relevant enough to the aims of this thesis. This process occurred over and over again, and even at the finish of editing these narratives, I still felt that maybe I could continue to edit. The feeling of never being finished was one that I have learned to accept and had to recognise as a feeling that may never go away.

Presenting the narratives as uninterrupted stories, I felt that the reader would gain a sense of the participant talking, rather than the researcher. I wanted the person to come through the page as the reader goes through each story. To achieve this, not only did I withhold including comparisons to literature within the narrative text, but tools were used when creating these narratives to present such participant descriptions. Writing 'long pause' or '...' for breaks in speech hoped to show these participant behaviours to the reader. Including words such as 'whispered/lowers voice' and 'laughs,' were included to add to the depth of the narratives. I wanted the reader to gain a sense of a person who had changed medication and was not speaking as fast or as fluid; a sense of the strong frustration the participants portrayed whilst talking; as well

as the embarrassment that many of them felt saying the word epilepsy or seizure while in public.

Reflection journal- 11/9/11: I am currently transcribing Andrew's second interview and it's going quite quickly, I think it's because he is talking slower because of his new drugs. His new drugs are affecting him a lot and it's hard to listen to him talk.

In creating the narratives, it seemed that the repetition of themes was a necessary inclusion within the narratives. Tracking the participants over time, they seemed to consistently repeat themes (e.g., frustration, sadness, fear, denial). These themes were included within the narratives to show the consistency over time for the SWE. Also, contradictions of earlier stories or topics were included to express the effect memory problems can have upon tracking the SWE's narrative. This will be evident within the narratives and discussed further within the narrative summaries following each narrative.

In presenting these narratives, it was seen that a summary of findings and reflections post each narrative might be necessary to provide a more substantial understanding of each SWE (chapters 6, 8, 10, 12). The observations of their mannerisms and voice intonations are discussed within these sections in order for the reader to have a clearer picture of the participant. Storied forms are discussed within these sections and will also be discussed later within the discussion chapter. Including these reflections was seen as a benefit to understanding the narratives and how I came to view their structure. Further researcher reflections on the emerging themes will be included within the discussion section.

4.7.2 How was the literature used?

Using the literature to develop interview questions (see chapter 2) as well as the philosophy behind my research methods, during the analysis process, literature was again examined for relevance within the resultant themes and holistic narrative. As I was analysing, the themes seemed to flow quite freely. However, once themes were discovered, I found it difficult to fit them all together! Finding it to be a hard puzzle to solve, looking at Carless and Sparkes (2008), I felt like my findings did not fit the narrative method as smoothly. Trying to find different ways of presenting the narratives to be more readable, I discussed these issues with my supervisors as well as tried different ways of structuring and re-structuring. In doing this, I wrote down personal questions in ways I desired to achieve the narratives for this thesis.

Reflection journal- 2/10/11:

For narratives, things to consider:

- 1) Structural flow- some things are not flowing together, should I use 'creative practice' and add in a few words so it reads better?*
- 2) Chronological order- do I keep this order although some themes don't exist throughout?*
- 3) Narrative tone-what's the message? Aims?*
- 4) Narrative structure- does each story fit nicely in a box, i.e. a structural narrative already in literature or is it something new?*

Looking at previous narrative literature (Carless & Douglas, 2008; Douglas, 2009; Frank, 1995; Lieblich et al., 1998; Smith, 1999; Zilber et al., 2008), I did not feel that this thesis would present narratives in the same fashion. However, I knew the end results

were informative and a valuable contribution to current literature, so this propelled me forward to continue using the previous literature as a guide.

At the end of the analysis process, literature (Arida, Scorza, & Cavaleiro, 2010; Arida, Scorza, da Silva et al., 2010; Eriksen et al., 2002; Goffman, 1963; Frank, 1995; Lieblich et al., 1998; Kleinman, 1998; Nakken, 1999; Nakken et al., 1990; Sirven, 2009; Zilber et al., 2008) was examined for relevance to the end narratives. Firstly, exploring narrative type, I found it difficult to find a ‘fit’ for these narratives. Upon finding that these narratives would be an addition to current literature, I had to distinguish between a new narrative type and themes.

Reflection journal- 27/11/12: Was hidden illness a story or theme? Is sport choice a story? Maybe the exercise experience of SWE does not fit within Frank’s (1995) storied forms? Maybe chronic illnesses differ regarding end story formations?

These thoughts were constant as I wrote my conclusions on each holistic story, and I have now concluded that they must be held true. People are different, coping and emotional response to illness and chronic disorders are different, therefore, why should story structure not be? Following this examination of the whats and hows of the narratives, I began to look at the holistic patterns to see if they matched Frank (1995) and Lieblich et al.’s (1998) narrative forms within holistic-content perspective. The narrative types and thematic results will be discussed in the narrative summaries following each participant’s narrative as well as the discussion chapter. Prior to presenting the participants, the suggested criteria for judgement for these narratives will be discussed.

4.8 Criteria for judgement

In the use of narrative analysis, I am aware that conventional judgement criteria (i.e., validity, reliability, etc.) cannot be used to fairly judge this research (Sparkes, 1998; Sparkes, 2002). Through considering different criteria (Carless & Sparkes, 2008; Sparkes, 2002), and upholding a poststructuralist philosophy for judgement (Richardson, 2000), the following are the suggested criteria to be used whilst reading these narratives. First, do these narratives make a substantial contribution to the greater understanding of the SWE? Does the narrative method adequately portray the lived experience of the SWE compared to conventional methods previously used within research? Second, does the narrative formation provide a coherent and readable overall narrative? Does the reader feel this analysis method articulated each story in a personable, yet intelligible portrayal of the SWE over time? Third, is there an appropriate level of reflexivity in regards to researcher self-awareness and self-exposure for the reader? Finally, have these narratives made an emotional and intellectual impact upon the reader? Does the reading of these narratives promote extended discussion on the psychosocial impact of exercise on the SWE? Prior to presenting the narratives in which these criteria will be used, the participants' background information will be shown, in order for you, the reader, to understand each participant's story more clearly.

4.9 Participants

4.9.1 Gwen

Gwen was recruited from the Epilepsy Action UK website where this research was advertised. We first met at a mutual location as she lived quite far away, and it was

easier for her to meet close to her work. Waiting in a hotel lobby, I looked at every young woman who came through the door, but you cannot tell who has epilepsy, why did I think I could tell? Then, a friendly looking woman made eye-contact with me and smiled and waved. That must be Gwen. In her late 30s, warm, easy to talk to, we jumped straight into conversation. Being a track and field sprinter from a young age, Gwen had been an athlete for as long as she can remember. She had always loved sport. But then her epilepsy stopped all that. Diagnosed with CPS at age 11, it was not until she began taking medication at 13 that the side effects of her medicine took its toll on her once fit body.

Talking to Gwen, it became immediately apparent that she had an exercise routine that she always wanted to stick to, and would become frustrated if a seizure prevented it. She did not like viewing her epilepsy as a barrier to her exercise. Married to a supportive husband, Gwen acknowledged that it is hard seeing others exercise, when she cannot do the same routine. As a recreational athlete, Gwen participated in running, cycling, and went to the gym at least two times a week.

4.9.2 Maya

Maya was recruited through a medical epilepsy centre in Southern England. Being the only participant that did not approach me through the advertisement on the Epilepsy Action website, I emailed Maya as I was told she might be interested in taking part since she was planning on becoming the first person with epilepsy to swim the English Channel! Interested to talk to someone that seemed to be doing a sport and an event that others might frown upon for someone with epilepsy, I was excited to meet

Maya. Meeting in a coffee shop near her home, I was instantly aware that she was a swimmer. Not only did the wet hair reveal her identity, but tall, with broad shoulders, she looked like a typical swimmer.

Having simple partial seizures, Maya was diagnosed with a brain tumour at the age of three and had subsequent surgery to extract it. After years of no seizures, at 13, the seizures returned as a result of a build-up of scar tissue within the brain. Now in her early 20s, and not one to feel sorry for herself, it became immediately apparent that Maya would not stop swimming for anyone. As a club/regional athlete, Maya swims at least four times a week, depending on seizure activity. Swimming mostly by herself, the question of safety whilst swimming was something I was interested in, yet she did not feel that she was in any danger.

Once our interview began, I was immediately struck at how intense Maya was about everything! It seemed she could talk forever, and I had to stay professional and be in control of the interview as she went off topic many times. Maya's interviews averaged two to three hours longer than the other participants, with the longest being over four hours. As a result, I knew her personality very well and had extra data that would not be able to be used as it was not pertinent. However, I felt that because of her powerful personality and passion for her sport, her input to this thesis was impactful.

4.9.3 Rose

Rose was also recruited via the Epilepsy Action UK website. Being my first participant, I was very eager to talk to her. We met at the University of Roehampton for our first interview. She was small, smiley, seemed very happy go-lucky, and also a little

nervous. Having driven all the way down south to visit friends for the weekend, I felt very fortunate that she was squeezing in some time to talk to me about exercising with epilepsy. Rose is in her early 20s, and has always loved being active. She was so friendly it was easy to fall into conversation with her and her warm northern accent.

Rose was diagnosed with epilepsy one year ago. Experiencing tonic-clonic seizures, Rose has only had two seizures, however, tests showed no evidence of the cause for her seizures. The initial uncertainty of her diagnosis caused her to feel shocked, uncertain about her future, as well as a bit down. Adding to her initial reaction was the feeling that no one understood what she was going through. Feeling very alone, she would often get frustrated and annoyed at her family's lack of understanding. Initially Rose did not know her triggers, but she soon realised that tiredness and stress was a common trigger. Rose felt that life had become more manageable with a change to a new drug, which resulted in less side effects. As a recreational athlete, Rose participated in non-competitive sports (swimming, running, and cycling), at least three times a week.

4.9.4 Andrew

Andrew was my final participant to be recruited via Epilepsy Action UK. On his first interview, Andrew, in his mid-20s, came strolling into the University an hour early because he did not want to be late! Eager to talk to someone else who had epilepsy, the sense I had from his initial call was that he was at the end of his tether about how he should deal with his epilepsy in regards to exercise. Prior to the interview, I was very clear to inform him that I was not a therapist and that the research was set by ethical

boundaries. I offered him help lines and an information website on exercising with epilepsy that he had never been to before. A visibly fit, easy-going young man, you would not think that there would be anything physically wrong with him. However, upon talking to him, it was evident there was an internal struggle about the stigma that comes with his disorder. Having tonic-clonic seizures since the age of 18, Andrew seemed to be overly sensitive of others opinions of him.

As a club rower, exercising at least three times a week, Andrew had been steadily moving up the boat, becoming a stronger and stronger presence within the team. He became an even stronger presence when he had his first seizure during circuit training. His embarrassment and fear of what was to come in every training session had a profound effect on his exercise routine. He expressed strong feelings of wanting help or someone to talk to who can provide answers for his exercise dilemma. At this point, it was re-discussed that I could not provide answers, but am here to listen and witness his story. This seemed to have eased him, and he seemed to feel very comfortable in talking about exercising with epilepsy.

4.10 Concluding thoughts

The next chapters present the participants' narratives over the course of one year. Each participant's narratives are separated by the interview schedule (i.e., first narrative, second narrative, etc.) This will allow the present chronological effect to be shown more clearly (i.e., any change/no change over time). Following presentation of the narratives, narrative summaries will be shown to provide more insight into physical reactions of the participants during interviews, personal reflections of the narrative process, as well as

discussion on storied form. The discussion chapter (chapter 13) will then examine the outcomes of these results using current literature and the impact it has for future research.

5.0 Gwen's narrative

5.1 *First narrative*

It's very important to me to keep fit. It always has been. When I was at school, I was really, really, really... fit! And did lots of exercise, and was probably quite renowned for being quite sporty. I think as soon as I started medication, I think about 13, I started to change a little bit. I felt what I could or couldn't do in terms of keeping fit was limited because of the effects of the medication would sometimes make me feel so tired. So, that kind of energetic, you know, season of, always being put in for the 100, 200 meters, started to slow, slowly decrease... But one thing I really want to emphasize, it doesn't stop me from trying... (laughing) It allows me to try to continue and continue to do it, but I do get frustrated sometimes. I have a very supportive husband fortunately, but sometimes I do feel quite tearful because I just, I just want to exercise!

When seizures do happen, I know for a fact that the following day, maybe 1 or 2 days after, exercise is out! I cannot do any exercise 'cause I'm absolutely exhausted from them. So I feel like just as I'm getting into the scheme of doing my exercise two or three times a week, I feel like I'm back to square one. And it can be a whole week, week and a half without doing anything and I feel VEERY frustrated because... I do my best to really try and keep fit and I think, rather than me, my exercise dominating what I'm doing, it's my epilepsy that seems to be making my decisions when I can exercise. Which I find very, very frustrating.

I'd love to say I'm going out for a run tomorrow, but you know, if I have a seizure, I can't do that. I don't know whether I will be well tomorrow, that's what I feel

frustrated about. I can't make any plans. It's the planning, that I find really, really frustrating... because I think it's only been, it's only been more prominent recently because I've increased the level of exercise I do. Whereas before I probably was feeling more, more tired. Saying like 2, 2 years ago ... it's a bit more ... if you don't do exercise, that's fine. But now I'm so, so keen to keep fit 'cause I'm in my late 30s and I really don't want to (laughs) not do anymore exercise.

Most of my seizures seem to be an indication that I've done, that I've overworked. It's almost as if my body's telling me, my brain's telling me, you've done too much. It's almost like a post-effect. And the seizure, having a seizure makes me think, "Oh have I done too much exercise?" Or, "God was I really stressed?" Or, "Oh, I must be really tired." And I tell you, I don't recognise it.

I'm less likely to have a seizure when I've done a run, than when I'm at the gym. Definitely! That's why I think it's sometimes safer for me to, to run, than it is to have 2-3 hours in the gym... I don't know if it's because I'm on different apparatus, or because obviously I'm doing the running, doing the rowing, or the cycling. I don't know whether if it's that concoction of exercise that makes it. But I think the HUGE important factor there is that I do think if I do have that gap, that gap from when I haven't been able to exercise as I've been away (on holiday), or just because of my seizures. And when I go back, I have this desire to fit it all in a week because I just haven't done anything... I don't know, all the seizures they just sort of make up for it as sort of say, "Ok, you didn't have any before, so now we are going to give them all to you now." You know? So then I'm back to square one because then I have to wait a week, a bit, before

something, finally let's me, I feel allowed to, feel I can do something... strenuous. I really, really am, I am conscious of that, you know? That strain on your body.

Ummm... but yeah it's getting that kind of balance right between, listening to your body and recognising when a seizure will come on and whether you want to go to the gym... Just challenge, just challenge it and think, "Am I gonna go?" I've got a slight, kind of, what I describe as a tenth of an aura something slightly going on, something not quite right. "Do I go to the gym, 'cause I haven't been last week? Do I sacrifice it?" Because often what I find, when I do go, seizures happen afterwards (nervous laugh). ... So, that I find particularly... yeah, just frustrating. I've almost learnt a way of encouraging that, I think my own way to encouraging that is by saying... "There's nothing I can do about it."

But I'm also in a catch 22 situation 'cause I'm also really quite determined. I get really, I can't win, when I'm prevented from doing it. It's very frustrating. I want to be really fit, well, not really fit, but I actually get out of breath, running up the escalators... (laughs) What I've noticed recently is, I'm not as fit as I used to be. I think I find that very frustrating. And I know I'm not getting any, none of us are getting any younger. But, I just want the option of being able to do it. Because of that restriction, I think the fact that my seizures and their timing, dictate the type of exercise I can do! Rather than me being able to say, "Hey, tomorrow I'm going to exercise." Or, "Next week I will go to that run with you Chris¹¹," or whatever, you know? 'Cause I don't know what's going to happen the previous days. I find that unpredictability, there's no pattern to my seizures. Stress and fatigue are definite triggers, but there's no way to prevent it. They

¹¹ Pseudonym for her husband

happen anyway. So, it's, I find it very hard to train (little laugh). I can't... I can't do that because, you know, you don't know when your next seizure's coming or going to occur. Yeah, I find that quite difficult really...

Uh... but I just find epilepsy is such a massive part of who I am as well. It's almost as if one part of me wants to get rid of it, but part of me thought, is thinking... but if it goes, well, I don't know if I would know who I am anymore, because I can't define myself by it. You know? It's quite strange, isn't it? I was thinking, I'm saying, I am who I am besides my epilepsy. But at the same time it's a huge part of my make-up.

I think actually, epilepsy doesn't just affect the person who's experiencing it, it affects everyone around you. And I think, he (husband) has to feel, that he's doing something to help. Umm, yeah I don't know.... Umm... I just think the people around you find it quite difficult to understand. Do you blame them? Nobody understands epilepsy anyway, even the person experiencing epilepsy doesn't really know much about it. All you can expect is the neurologist to understand it, but they do worry. I think they do worry. And they do worry, PARTICULARLY when I exercise they worry. That is when they do say, "Are you ok? Do you think... do you think you might need to relax?"... "No, I'm feeling fine for tomorrow!" I get those kind of, particularly, more so from my mum than my husband, but umm... Umm that kind of overanxious, overprotective behaviour... after I've exercised. "Are you sure? Oh you do too much!"... I just want to be like, "It's ok, it's fine. I can look after myself."

Like I said, Chris is very, very supportive. He does worry. And that worry, just two-folds 'cause that worry is, "Every time you go to the gym you seem to have

seizures.” I’d much rather deny it, and it’s a coping strategy. I think, I think it’s a coping strategy because... “Do you mean I can’t do any exercise? What am I meant to be restricted to doing? Just walking, taking a walk for half an hour? That’s not what I want to do. I want to do some strenuous workout.” He said, “Look, look, this is what happens.” I do talk to him about it. Umm, as to kind of an answer... I don’t know. I keep... I’m quite persistent, persistent in that I keep trying (laughs). But, I guess... I live in the hope that one day I don’t have those seizures, and they just disappear (laughs)... And it is because they notice that connection and they worry that every time I do something, that it’s, that a seizure is going to happen. Umm... just thinking, it’s sort of right, it’s annoyingly right. Another part of me thinks, I don’t want to hear that. I want to hear you saying, “It’s ok to exercise, it’s ok to do these things. You know your body more than anybody else, you manage it well. You can cope.”... But that doesn’t always happen. It’s kind of, one’s heart tends to take precedence... I can make these decisions. Also, things at home said to me more so, rings too many bells, that I can’t do anything! You’re highlighting the fact that I’m incapable. That’s such a strong word, but that is sometimes how I feel!

I think... If, I run with Chris, then, uh... yeah, I guess I feel a bit more supported, guess you could say. It’s weird, I don’t actually worry or anticipate having a seizure before. No, no I go with it. I say, “You know what, I’m not going to let it stop me from doing it,” and I just go with it. But obviously, if somebody’s with me, you know running with me, then I have that added security in the case that if something did happen, then that’s fine. But it doesn’t stop me from doing it on my own. I don’t think it necessarily... prevents me. If I did an hour’s run, or an hour and a half’s run with Chris, if it’s

particularly strenuous, I don't think it would stop me necessarily having a seizure the following day, just because I had someone with me at the time... I think he feels, he doesn't offer in terms of feeling insecure about me going on my own, no... not at all. No, he knows I can go off on my own. He has no problems at all. He has got confidence in me. Knows I'll be fine, I'll be ok. In fact, if things were to happen, it's usually post-exercise anyway... I just constantly choose not to go with him sometimes. He is nice, if he chooses to say, "Oh I'm just going to go out for 20 min." "Oh, I'll come with you." If he is going to do an hour and a half, I can't do that. I'm not there yet (laughs).

But I am envious of him in a way, because he can come up and say right, "I'm going out tomorrow, I'm going for a run in the park"... I don't know whether I will be well tomorrow, that's what I feel frustrated about. I can't make any plans. It's the planning, that I find really, really frustrating. 'Cause I'd like to train for a 20K that he's doing in Brussels, I'd like to do it with him. I just don't think I can because I don't think I can get the training in. Because if I'm ill and I have the seizures, then I won't be fully trained, and I find that very, very annoying. Very, very frustrating... (long pause)

That incapability, you know, one of my very close friends exercises a lot. She's done 10 marathons. One of my closest, closest, dear friends, she's a really good runner. And I find it really, really difficult to hear about her experience. I find it really, really horrible. At, on one level, if I'm very, very honest, I was completely jealous. Because I just thought, you can just go out and run whenever you like and so the only comparison is the gym, that it's there for me. If I was to have a seizure, I can't go out the following day! Do you know what I mean?! Training for a marathon?! I would train for one, but I can't! And I find it very, very frustrating.

I try to challenge myself a bit... (long pause) It's interesting, it's interesting that you should ask that because I'm conscious when I'm challenging myself constantly. You haven't done this for awhile, at least you've gotta push yourself here. You know? Haven't done any exercise for the last week, you should be able to go fast. I often basically go the same routes... so... I often spend most of my time, thinking, "Did I do it quicker today?" Or... not always consciously monitoring it but... part of me in the back of my mind wondering, "Was I going faster today?" The body just knows anyway. I don't think there are always things that you can identify, but sometimes you just have such a good run! You love the days where you think you're doing really well (laughs). There is not always a given reason for that... yeah. So, yeah, I guess I do try to challenge myself...

I think I'm trying to prove to myself that regardless of my epilepsy, I can actually do... I think somewhere in my mind, subconsciously, I think I'm trying to... uh ... say well, if Chris can do it or Anne¹² can do it, their runs, there's no reason why I can't do it. When really, if I'm very, very honest with myself, I feel I have to challenge myself most of the time. I should ... not ... challenge myself as much as I sometimes do, as the effects are there afterwards. Umm, it would be interesting actually, to go on a few runs, I might try this out, to go on a few runs where I don't challenge myself so much, and just take it at a slow pace. Just do 25 minutes, 20 minutes. See what, if the same effect occurs ... I'm sure I have in the past, I don't constantly challenge myself, but I'm more likely to say "Come on, Gwen you've got to do this!" I don't consciously think because of my seizures, part of me, maybe it's a really unconscious part of my mind

¹² Pseudonym

thinking there's something slightly different about me and because my body is a bit more aware than somebody else's, you know? Prove to myself that I can do it. Prove to others is the least important thing, it's proving to myself that is important, I think. Proving to myself, and if I manage to get through it, then oh, ok, that's fine. That's alright then. Yeah, seizures haven't taken over (laughs). So that's probably, why I do it... But then as I say, you know, it's the effect of having seizures and then back to square one and stuff, and then I start feeling sorry for myself for a short while, till I'm back again! So, this is a slight (little laughs) crisis, I don't know how to get out.... yeah... but, I'm sure many people can identify with that.

Umm, I tell you one thing that's really worked... and I, it's my own fault for not fitting it in, which is a very, very good exercise, is yoga. And yoga has really helped me relax... and it's supposed to be really good exercise, part of me just thinks I should just stay and just do yoga because then at least I feel like I'm doing something. Umm, seriously considering doing that... I've been encouraged because I think, obviously it helps with stress levels as well. It takes, it takes away the trigger, but also it feels like I'm doing something a bit... But yeah, I think that might be an option.

But, I'm not ... and I guess the emphasis is on learning not learnt, LEARNING to cope with it that much, much better as time goes on. 'Cause I think I'm just learning to cope and say, "You know what, that's probably just the way it is and that's the way it's going to be." I'm not quite sure what else I can do to change that. 'Cause as my seizures go, that's always going to be the case... And it's frustrating, but at the same time, I don't really know what else I can do to make it ... more easier than I do already. There's nothing that I can like, do to make things better...

5.2 Three months later- Second narrative

There is a slight tenuous link, but I think it's a link nevertheless, in that, since I've been going swimming as opposed to running or going to the gym, it's really helpful to my seizures... It's better to do three lots of 30 minutes of a gentle swim, and I love it! ... 'Cause I feel, it's interesting because you'd think it's more dangerous to go swimming if you have a seizure. But to me, I just feel more... I don't know... I feel more in control, I feel more relaxed....What I have found is that swimming is better than running cause there's something really gentle about, even though you can do really vigorous swimming, there is something very gentle about swimming. It's just different to doing, you don't feel like you've done a workout, well you do in a way, but it's doesn't feel... too draining. Well at least not initially. I feel quite invigorated... Generally, it just feels better for the body, for me anyway... Can I read something out because I think it describes... This is on April, 13th... *"So I went for a 30 minute swim, feels really good that I can do a relaxing, yet at the same time energetic exercise. I really feel like I can do the exercise without worrying that I'm exerting too much pressure on my body. Feels quite different to a run, but no less effective."* And I think that is really important because when I would go for a run or go to the gym, I could guarantee a seizure afterwards. But when I go swimming, I don't always get seizures. I mean I might do, but I don't think it's necessarily connected to the fact that I've gone swimming. It's not immediately after, for example.

Uh... maybe because I'm using myself in the exercise, in what I'm doing... I just think, take this lane and whatever I'm doing in this space, emotionally, and I just go with what I have to do. And it's a really nice feeling that I'm kind of, just get in there

and just do it and just enjoy the experience. It's something that's very, quite relaxing... That's different to the gym. It's not always that same feeling, I don't know what it is! (laughs)... I think 'cause I'm really focused in the pool.

But there's a bit of a catch 22 to that because sometimes when my mind and my body goes to a relaxed state, then I'm more susceptible to seizures. Because I know when I'm really busy, at work, I NEVER have seizures, EVER! Because my mind is so focused. This is interesting cause when I was swimming, my mind is so focused, I never have any during that time.

When I go, I pretty much count the laps, the lengths I'm doing, so I usually go for about 40 minutes and I don't stop. So it's quite kind of non-stop, gentle... but I do alternate between breaststroke and try to make it more vigorous. Because I'm aware I don't want my body to get too used to doing the same amount of exercise each week either, otherwise I don't feel like I'm doing anything. So I'm starting to increase it slowly, but I'm also kinda conscious I guess. I don't want a major, major change in case I start noticing a shift. If I start getting really, really enthusiastic, maybe that's going to put my body under stress. But, no, three times a week at that length of time has actually been really, really helpful. At least for the moment I think that's quite good for me. And yeah I just generally feel quite physically better actually... It's been fairly vigorous exercise. Yeah, well I say vigorous...

And then here, another day I would like to read, I went a really long time without any seizures, which was about a month. Which is a really long time. "*30 minute swim today, not sure if I should go whereas had a few seizures previously.*" Then there's a

little asterisk there, *“This is the longest time without seizures in months.”* So I think it’s about 5 weeks. *“I’m writing this to tenuously taking up swimming again as opposed to gym and running and I’m interested to see if it happens again. And in the past I wouldn’t have put my body under any strain. I had a sleep for nearly 2 hours previously when I had seizures, but I didn’t feel the need to do that. I decided that a gentle swim would do me good, I felt much better for going and it seemed to help me relax both mind and body.”* So that’s great, that’s really, really great. And the weird thing is, when I have, when I used to have seizures prior to going to the gym, I couldn’t actually go, if that makes sense... So, um, it would be interesting to see if anyone else has had this connection. I’m just so, it’s interesting I think because I switched exercise, it kind of gives it that feel of how different that is because I’ve had the feel of doing both types of exercise... Definitely something going on. I don’t pretend that doing that kind of exercise, all my seizures are going to go, but I definitely think it’s had an impact.

I feel more in control, that’s the biggest thing. I feel, I keep using the word relaxed, but I do. I don’t feel like I’m compensating for the fact that it’s not as strenuous on the body as a gym exercise, I don’t feel like I’m compromising. It still feels quite relaxing. It doesn’t feel like a chore. You know with some exercises you feel like, “Oh, I’ve gotta go for a run.” I actually just really enjoy doing it. I don’t really think about my seizures per se. I think occasionally it pops into my mind, but I get so invested into my exercise and the effect it’s having on me and how much I’m enjoying it that it doesn’t really come into the equation. At least not during the exercise anyway. Maybe if I had a seizure on the day or something because I might be a bit more conscious of it, which means I might reduce the amount, something like that.

Yeah, I mean seizures are happening, there's no denying that they're still occurring. And they'll occur definitely in clusters, which has helped me identify the pattern more. They happen in clusters and then I can go through a period of exercise where they'll be none at all. ... (looking at journal) Oh yeah, there was a day where I had a seizure the day before and I felt, I was a bit worried about having another one and I really wasn't sure whether to go swimming, and I went! And I felt 100% better for going! I remember that PARTICULAR day where I was really apprehensive about whether I thought it was a good idea.

Mentally you say like, "Right I'm going to go." I think the days when I say "Right I'm definitely going to go," I'm able to do much more on the day because I have that much more enthusiasm to say, "Right!" And I especially think it's the case when I've had seizures a couple of days before that's prevented me from going. So I think the impact psychologically of not doing exercise for me, is quite big, because I start getting frustrated and think, "I can't let my seizures stop me!" And occasionally I noticed a time where they have, I'm not denying they have. But I've also done it the other way and kind of said, "You know what, I've only had one this morning, it's OK to go after work today." If I've been alright the rest of the day. If I've noticed a cluster and there's been quite a lot, it has prevented me from going, 'cause I do listen to my body first before I then go into the pool and do loads of strenuous exercise.

'Cause I swim quite energetically at the moment, I don't like just going and doing a calm swim. Which is sometimes quite nice to do, but I tend to do it quite vigorously, and I think if I've had seizures the day before, I definitely won't be able to go swimming afterwards. This was some of the other effect, if I've done a very vigorous

swim, if I've had a little break of maybe two or three days, and then do a vigorous swim, sometimes that can induce seizures... Umm, which makes it sound like the effects of it are quite negative. In a weird way as well, on the other side, what I've noticed when I do my exercise, generally, I don't get as many seizures as I used to get. It's a very slight reduction, because I've been doing my exercise, generally you feel better as soon as you've done it! I think, there's just some patterns if I do it quite vigorously... and that's when it's more likely to cause a seizure.

I'm quite hard on myself because I feel I should be doing at least twice a week, and then it doesn't happen, so I feel like I have to over compensate for that, and then that's when it's more likely to happen I suppose.

This is the thing. I am counting, literally counting laps, and I did about 40 last time and I go, "Right I'm going to try to do 50 this time!" But there are some days I do actually listen to my mind and body and say, "Well, you know what, I had a seizure yesterday, I feel a bit tired. Just don't do so much." 'Cause I know what the effect of it will be. So I'm quite conscious of that, in a way. But in a weird way I think, the more I think about it, the more it will play on my mind. So it's a really hard, I would really love to just go to the swimming pool or gym and just do what I have to do without thinking of the potential consequences of it.

It's horrible you go through that kind of sort of period, sort of great for you, you know your own threshold. When you sort of exceed that, it's great! And then suddenly, it's wham, bam! ... It's weird because, yeah, it's kind of fighting a losing battle in a way. *"I had another, further seizures yesterday, so my health won the battle and I was unable*

to go swimming. Felt a bit sad that my routine was messed up a little bit. Feels like a catch 22. When I know it's hard to swim, but going for a swim clearly helps me relax... Another exciting day, now I've had two more seizures and don't have the energy to go."

So, yeah, it can be a bit, I find it quite frustrating because I think, if I didn't have any seizures at all, I would be probably be swimming 5 days a week. I think, mentally, I've got the energy and motivation to do it. But just physically and medically, yeah whatever, it just buggers up my whole routine! (little laugh) I find it very frustrating. And I just perhaps try to come to the realisation that that's just the way it's going to be. And I just have to, it's almost as if I'm fitting my exercise around my seizures. Rather than my seizures around my exercise, and that's what I find very frustrating. It's the one that tends to dominate; it's nothing you can do about it. If you have one, you have one. You can't control them. And since I'm not on any medication at the moment, umm, so they happen as and when... Umm, but I get frustrated because I kind of think, just because I have seizures, does it mean I can't keep fit? That's the thing that I get annoyed with. Does that mean other people are, are just able to go?

I have, it's interesting as well, I spoke to one of the gym instructors as well, 'cause I wanted to do some toning, and he showed me some, how to use the toning machines. I do a bit more vigorous exercise in the gym. And I'm kind of really apprehensive about doing, putting too much pressure on myself, on my body. 'Cause I think, oh gosh, it's OK at the moment, I'm getting a few seizures, but it's OK. I don't know whether to up the load, with a different form of exercise. I don't mind upping it a tiny bit with swimming, because I feel comfortable with that. But actually going to the gym and starting another routine, on top of swimming, I'm not sure of whether that's

too much. But if I do, I'm going to make a conscious effort to see how that affects me I think... It would only be about 20 minutes before I go for my swim... But I haven't incorporated that into my routine yet.

I think it occurred to me one day, "Oh, maybe I should tell someone in the pool that I have seizures?" Oh I don't know how I would feel about that because I don't often like making a fuss anyway, and what happens if they get sort of panicky? They might start, they hear the word epilepsy and they might start freaking out! (laughs) They might think it's something really severe... Why did I not tell the lifeguards? I think purely for that reason, I think unless they had a good explanation of the type of seizures I have, and how it affects me, it would lead more to panic, than useful productive action. But that might be my own bias, I'm not sure!... But I guess I think I'm a bit stubborn because part of me also thinks, "Oh I'm fine, I can handle this, just because I have seizures doesn't mean I can't go for a swim." I think that's partly why I've kept it to myself and haven't mentioned it to them. Also because they might freak out a little bit. I often feel it's quite misunderstood and I don't want to cause more hassle than is necessary. And also, I don't want it to take away the pleasure from my swim. And I think if I tell them, I'm going to have these cat's eyes looking at me all the time, so I don't want, I just want to swim! I don't need to, maybe that's my paranoia, I don't know. But I just feel like I just want to go there and it be my own space, no one knowing, no one knowing that I have (lowers her voice) epilepsy, and I can just go and do my exercise and leave. And that's why I've kept it; so far it's been ok. So, I guess it's something that might come into my mind again at some point, but...

It's been really helpful for me, I have to say. It's been really helpful for me, you know, monitoring the link between exercise and having seizures. There's definitely something going on. I don't pretend that doing that kind of exercise, all my seizures are going to go, but I definitely think it's had an impact.

5.3 Three months later- Third narrative

Umm, yeah, mixed bag. What can I say? Yeah, mixed bag. Still having, it's quite weird, quite sporadic seizures. So, having seizures in clusters and then not having them at all. But I'm still trying to maintain as much of my exercise as possible. However, what I have noticed, the times where I have my clusters of seizures together, there's no way I can do any exercise, I can't do any. So I find it very, very, I think frustrating. And really, umm, just, I don't know, annoyed that I have the motivation to do it, but physically I'm just too exhausted and run-down...

I'm continuing to do exercise if I have time. But prior to that, it's been a bit up and down. There's no real pattern, I don't know if it's the same for yourself, but there's no real pattern. So, umm... yeah... it was a bit strange that, I think, there was a whole time without having any... but I don't know if I owe that to exercise? I don't know. I haven't been doing any different amount of exercise those two months. Nothing, sort of, specifically different... But in that proper sort of two months, just under two months where I had no seizures at all, my exercise was brilliant! And I, I was in a flow. And I think psychologically I just think, "Ooh, this is looking quite good, it's not going to happen again!" Even though in the back of your mind you know it will. And then you have one and you think, "Gosh, ok. Back to square one"... Umm, I don't think I have

had a seizure with exercise, and I know... I'm pretty sure I haven't 'cause I think it would have stood out for me. No, I might have had one the following day. But never, I'm pretty sure; I definitively don't have it straight after. Worst case scenario, I go to the gym, 6:00pm and I have one about 9, 10pm. Never directly straight after exercise. Because it makes me feel a lot better straight after exercise.

Probably exercise three times without fail. Which is good for me, 'cause I'm so busy, so it's hard to fit it in. Umm... but now it's at least once, great if it's two, fabulous if it's three!! (laughs) That's how I see it at the moment... I couldn't exercise two or three times because of my health. I had little ditty ones, but not proper ones. And then I had one yesterday in the morning, and I thought, "Be damned, I'm going swimming!" And I had a really good workout! I had one of the best workouts I've had... I'm going at one o'clock in the middle of the day, there's hardly anyone there. Uh, and I came out, and I thought, I was so pleased with myself for going, and I felt, psychologically, emotionally, and physically better for doing it. I'm just wondering if I could probably do it all the time... It was brilliant, I felt fabulous for going! I don't know if that's just because psychologically, I felt better for going. Also physically, obviously, but psychologically because, I didn't want the seizure to get in the way in doing it... But in terms of looking at the patterns of exercise, it can be very ... (motions with hands, up and down- does whistling action). But as I say, generally I don't do more than three. It could be a week, don't think more than 2 weeks without any exercise, never. But I, that's the first time ever, I think, literally. I might have done it indoors, because we have a rowing machine. First time I did any exercise in the gym or outside, on the DAY I've had a seizure. I've gone the following day, but I've never gone on the same day, never!

It was really weird. I was really conscious of it, I was really conscious, and it was really weird. I just thought, OK, clearly people obviously don't know. I just thought, what happened if I had one in the swimming pool? 'Cause at the moment I'm not remembering, I'm just losing consciousness... I don't know how a seizure would affect me in the pool. I was thinking about that! 'Cause ordinarily I lose, well kinda lose consciousness, and become very vacant. And I make these kind of grunting noises, so I'm told. And although they're not very loud, they may be quite noticeable. If you're swimming in your normal breaststroke and then you hear these grunting noises from this woman who's swimming next to you in this lane! (laughs) Umm... 'cause I think people wouldn't necessarily identify what it was. Complex partial seizures are hard to identify. 'Cause people stereotypically I guess have a notion of seizures that people just, collapse and you shake, convulse, things like that. I wonder if I would just go under the water. 'Cause you'd just lose control!... I do know that, because mine are very short, they're only about 20-30 seconds. In certain situations, I can acknowledge that something's happened. Or I can get a premonition, "OK, something's weird; I think I'm going to have a seizure." I have been known to continue, let it happen and then almost go back to where I was, realised something's happened, but just carry on with what I was doing. But I don't know if I was swimming, if that's going to be too late because I would have been going under water.

I know for a fact that with the nature of my seizures, if I was to have maybe one or two seizures in the morning, typically that would rule exercise out. Because one, it makes me tired. And two, I get real physical, I may have mentioned, I get real physical

symptoms afterwards. Real, sort of IBS¹³ type symptoms, my stomach just feels like acid, it's horrible! And, I wouldn't enjoy the exercise, I think. It's weird, I didn't have too many after effects with the seizures I had or the one seizure I had in the morning... So I just think, makes me wonder, so how come I managed to let it not let it take over at that point and all the other times it's dominated what I can or cannot do? It's bizarre, it's bizarre. Sometimes I think I've got quite a lot of control over it, and sometimes I don't.

But it is such a vicious cycle, it is such a vicious cycle. You know, you have to make a decision, and important decision if you want to break that cycle. And almost, take a bit of a risk if you've had a seizure. And just say, "Ok, gonna do this bit of exercise." Otherwise it's that cycle of if you have seizures, you can't exercise. If you can't exercise, that sometimes makes you feel a little bit low, and frustrated and that sometimes can make you feel run down and induce more seizures. And it's that whole cycle! And unless you break that cycle and start to exercise, a bit like the example yesterday, when I had the seizure and I thought, "No, I'm going to do it" and do it. I felt REALLY so much better for having doing it. So the cycle looks quite different! Because I start to feel better and feel better about myself and that impacts on my health. And my overall well being, really. The trouble is that cycle isn't always predictable. That's the thing. And I think that is the HARDEST thing, the unpredictability of it, really. Umm.... and I say as I ... I don't ever envisage having a proper routine of exercise, ever. I don't think I could have it. All I can have is the motivation to keep to as much as a regular exercise pattern as I can. Unless it's something DRASTIC through changes in medication or hormonal changes through pregnancy. I can't see anything allowing me to

¹³ Irritable Bowel Syndrome

have a set regime of exercise. Umm... because you do have to listen to your body, clearly. And maybe I was a bit of a naughty girl going swimming yesterday but I did, and you have to weigh up the pros and cons a little bit, to be honest. Sometimes you have to have so much determination to do it, no matter how weak you feel. I actually got to the point where I got to the gym and thought, “Oh, should I, shan’t I?” You go through that self-talk of sort of... “Should I just go home and go on the rowing machine for 20 minutes?” But then I wouldn’t feel like I’ve done a proper workout. But it’s better than nothing. But no, gonna make sure I do it! And yeah, 90% better, if not more as a result. I need to perhaps remind myself if that happens again. And to try and go, but go at busy times. A time that there’s nobody in the pool might be too risky. Just be mindful of what the steps you might take.

But I think, the reason why I went on that Tuesday, Wednesday... Monday, I think the particular reason I went there is because I was so ... I was so keen not to let them get to me. And the rest of the time they had. And ... and because I put on a little weight over Christmas (laughs) so I just want to really get those few pounds off! I just think, “Well, does that mean people with seizures can’t have regular exercise? Hmm? Do I have to give in, give in to my health?” But then how much do you balance between giving in to your health. Between actually saying, “Well, look after your health because you’re physically exhausted because you’ve just had seizures and therefore you shouldn’t exercise.” And I find that really hard! I think it’s just a personal thing, you have to just listen to your body. But then at the same time, try not to let it get to you too much, and that’s a really hard thing to do!

I've just had occasional moments of just feeling, like just so low because they come back. You know what I mean? 'Cause they just get you so down, psychologically and physically. And then I suddenly get picked up a moment, "No, right, can't let it get to me," and then I start my exercise again. Umm... yeah, I'm just so envious of people who can do it as and when! I think it's the fact that you don't have control over them. That it determines your level of activity that you do. I'm curious because I've always thought, "If I didn't have seizures, how many times would I be exercising?" I'd say, at least four or five times a week, I'm sure I would. 'Cause I was always really sporty. Umm, before I was even diagnosed. And then suddenly you're diagnosed. I think psychologically, you kind of go, "Ooh, ok. Does this mean I have to take heed?" and start, kind of, not doing so much. But yeah... I'm so frustrated! Because I hate the fact that I, my seizures, control the amount of exercise I can do... So yeah, it is important to look after yourself as well. And I think I've slowly come to realization actually, you know what, my body's not the same as everyone else's, and I do have to listen to it and adapt slightly. It doesn't mean I can't ever do exercise... But I don't like, the thing is I don't think I'll ever have a regular routine of exercise.

What, up the amount of exercise? I do, but I'm also quite conscious that if I do that, I'll over work myself to the point of, it would have a secondary effect of me having more seizures as a result because I've put too much exertion on my body... So I'm quite conscious. I don't know, I never really tried it. I'm sure in the past. There have been times where I have done 4 or 5 consistent days over a couple of weeks of complete exercise. But at the moment, I don't know what it is, but something tells me that if I increase it to 4 or 5 days, let's say I had a week without any seizures, or two or three,

whatever, I don't think I'd just go straight into doing 4 or 5 days of exercise. For me, it's also about having a steady amount of having good straight exercise rather than going straight for the kill. I'd do it and then worry about if I'm going to pay for it afterwards. Also time, I don't have time to do that right now. A bit of a terrible excuse, but it's true none the less.

Yeah, I was diagnosed at 11 and I had a neurologist outside London. And it was pretty much, "Don't do this, don't do that." And I think it was probably more for their own safety, their own anxieties projected onto you really. 'Cause, uh, they want you to be conscious and should notice things you should and shouldn't do, so to speak... but umm, you have to be mindful of me, I'm a bit delicate. Can't do much exercise! I don't know if those are just my own insecurities, but... umm... I obviously think that, as well, that people feel that about you, a little bit... But my neurologist now, he's not quite, "Don't do anything at all." But he's like, "What would you like to do?"... So it's nice, it's encouraging, but I don't think he always thinks about the consequences of things... I've actually been advised not to, more by my husband. I've actually said to him, "I just want to go, Chris, I just want to go! I'm so frustrated!" Because I hate the fact that I, my seizures, control the amount of exercise I can do. And I find that really, really frustrating.

Actually, seizures just form part of my identity. I was just saying to Chris, "I don't know what I'd do if I didn't have them." And I don't know what it is, because it's certainly not a dependency on having them, but it's just so much of who I am. If I stopped having them, it would be just too weird. I don't know?! Weird in a nice way and I'm sure I can adjust quite well!! (laughs) But it would, yeah, but it's all fantasy really,

isn't it? But I think for me, it's just become a part of who I am really, so I just... just... yeah, it would be a big chunk taken away, but I'd be able to exercise a bit more.

5.4 Four months later- Final narrative

It's been a bit up and down. Definitely... Uh, stress has brought on more seizures, starting my course¹⁴, and lots of deadlines in my course... but in terms of exercise, it's (swoop down with hands) very low. And I've had a couple of moments, couple episodes, like weeks, where I was able to do my swim, do all my laps, and then I just had a series of seizures. Ooh, I've said that quite loud. (lowers her voice) But yeah, definitely had quite a lot because I just feel physically drained. (we move recorder closer to her... she looks anxious)...

So yeah, exercise's dropped quite dramatically because my health has been worse off and I think that's been set off because I've had loads to do at Uni. So it's been an escalating effect. And it's been very frustrating! 'Cause I can't keep fit, and it feels like my health is determining what I can or cannot do. Umm, especially with swimming. And even cycling! 'Cause I cycle quite a lot to the station from where I live, it's about a 25 minute cycle. 'Cause I can't drive, I have to cycle everywhere. And even then, I worry about cycling on the road if I had a seizure. So I just say, "Don't do it." So I'm resolved to public transport! So even my day to day sort of cycle I can't do, because of that reason.

Umm, and I think that, it's weird cause it's a catch 22. 'Cause when I have seizures, I can't go. And then I'm worried to go 'cause I might start having seizures.

¹⁴ Started doing a PhD

And I don't quite know what pattern it is. 'Cause I know I've been in a period of time where I've been able to go to the gym and do loads of exercise, and loads of swimming, and haven't had seizures for a month. But it's difficult to know if my seizures are happening more because I'm exercising, or if it's just because I'm going through a general pattern, where life is okay and I'm not too stressed. So I don't really know what to attribute it to. And it gets into that kind of vicious cycle where I can't then go to the gym and have more seizures. (laughs) It's difficult to really know what factors I can attribute it to... It is very hard. It's just so frustrating!

The other thing as well, which is very frustrating is, my husband is training for a 20K. I would love to do it with him!! But, I can't possibly be open to training for something like that, 'cause it's so unpredictable. Umm, I could have a seizure on the day. Or, I can't train consistently enough to get to a point where my fitness levels are pretty high... That's the annoying part isn't it? They just come, don't they? That's what would make training for things so impossible. 'Cause they just, it's just too irregular. If you can't identify a pattern, you can't plan to train to do a run... There's no way I can plan my life, my exercise around that 'cause it's just too unpredictable.

Umm, I don't think I've ever done any exercise on the same day I've had a seizure. That would be, I couldn't imagine it. I would be curious to whether some people do that, but... I just know my own self and my own body and I just don't feel like doing it... But I think, even if I had seizures, and had a few of those, I still wouldn't feel that I could do exercise on the same day... Like today for example, I've had three and I feel ok, sort of. But there's no way I can do exercise now, no. I feel too like, I wouldn't get the most from it anyway. I think that's the key point, I wouldn't get the most from it...

but yeah, I don't think I'd enjoy it. When I don't have seizures and go and exercise, I always really enjoy it.

I think as well, I am at the point now where I have to say, "You've just got to listen to your body. Your body's telling you don't do exercise, don't do exercise."

'Cause my body just gets, run-down. I think it's my body's way of saying, "You know, your seizure was quite full-on, just relax. Don't do any exercise"... And all the effort you try to make it not dominate what you do. It's impossible for it not to. I suppose that's the MOST difficult thing. I find, anyway.

Sometimes I wonder, doing a thesis and having this, oh god! Sometimes I kind of think, "Why? Am I supposed to be doing this? Why am I making my life so difficult?!" (laughs) You know? I have to take into account that my health isn't that good. Does that mean I have to, it should prevent me from doing things? That's a question I give myself ALL the time. 'Cause I kind of think, yeah... I don't know... I kind of think, "Well, what happens if I didn't have this? Would I still be doing the same thing?" Part of me thinks, it makes me more determined! ... Because of that, because of that ... that I've got a long-term condition, it makes you feel almost a bit more, I won't let it take over me. I can't do that. I think that's almost more present than the former thoughts of just doing my stuff. I would be lying if I sometimes thought, "I just want to give up, give up my whole studying and get fat and don't exercise at all!" Just so I have an easier life. I would be curious to see how other people with complex partial seizures do manage? How different it is ... in terms of exercise with each individual? 'Cause I'm sure, as we were saying earlier, it must differ.

I'm trying to do some more relaxation, to do some, yeah sort of breathing exercises and time out to sort of keep my frame of mind a bit, whole really.... I started to go to yoga... and it was lovely, really relaxing. And, if I'm honest, I don't know if it had any effect on my seizures... I haven't done Pilates. I've done tai chi. I find it quite... relaxing... actually wonder actually, after you saying, if the yoga would induce any seizures or anything? 'Cause it relaxes you on one level, but it's actually quite strenuous exercise... I'm trying to make it as part of my regular routine. But I'd be lying if I said I did it as often as I thought would be helpful or more helpful! I probably do it ... umm, a few times a week. And I do diaphragmic breathing and progressive relaxation exercise. I used to do meditation, and used to find that really helpful. I've got the feeble, terrible excuse of not finding the time to sit down and do it. Whereas, you know, the breathing you can do anywhere. And potentially the progressive muscle relaxation as well. Yeah, and umm... I think I'm trying to get into the pattern of doing it. Because I know when am relaxed, there's less chance of me having a seizure

Umm, I wouldn't do relaxation before exercise, I don't think. I might do some stretches. I don't think I've actually done the relaxation prior to doing exercise. Although it might put me in a better frame of mind... I do it, at times after work... I've got a couple of pieces of work for my course due, or something. So I go, "Right, I'm just going to do a little bit of relaxation so I can focus." But again, it's not, it might be two or three times a week, it's not consistent for me to feel, "Yep right, this is what reduces my stress levels." I really should do it as part of my routine, because I really think it does help. Would be interesting to see if it does help, and the impact on my health.

It's interesting to explore really. It's interesting what you say, because sometimes, maybe because I'm tired, when I'm feeling very relaxed, sometimes my brain goes in that mode, cause I'm floating and it almost allows a space for those déjà vu feelings to come filtrating in. Does that make sense? 'Cause you're kinda feeling, oooh! 'Cause you're feeling a bit floaty, and a bit open and vulnerable in a way, that could bring on a seizure in itself. Sometimes when you're constantly active, you don't give yourself a lot of space for that type of thought. Until you calm down, like we were saying earlier, until the after effects and that brings on a seizure.

Probably, the frustration, the absolute frustration that your epilepsy has control over, deciding for you, the level of exercise you do. Rather than you being able to make that decision. Like, "Right, I'm going to do three times a week of running, or going to the gym, or swimming." And I think that is the one point I want to get across. That's the question even! Can people plan their exercise routine if they have epilepsy? That would be my question, that would be my research question. Can people plan their exercise? ... Do people just go into the gym when they've just had a seizure, or... It might affect Joe Bloggs very differently. Maybe Joe Bloggs will say right, "I've had a seizure, but I'm determined to go." I know I can't do that... No, if I'm honest. No, body definitely has more control over me. Umm.... no, 'cause it determines what I can or cannot do. Indefinitely!

6.0 Gwen- Narrative summary and reflection

Gwen's narrative presented an emotional angst in regards to her desire to exercise, feelings of a loss of bodily control, and the resultant limitations epilepsy caused in her exercise life. Witnessing a narrative type not yet seen within literature to date, Gwen's holistic story was presented as a "vicious cycle." This cyclical narrative over time was found to be an exciting result of this research.

The following discusses Gwen's narrative over the course of the year. Firstly, an overview of time's influence on the narrative type will be discussed. This will be followed by reflections on each narrative and theme extraction. Finally, concluding thoughts on the formation of these narratives.

6.1 Narrative over time

Time played a part in Gwen's story as she seemed to change her mindset and behaviour over the year (e.g., adding different exercise routines, listening to her body more), yet there was not a complete change in narrative structure. Following a cyclical narrative type (will be discussed in the next section), Gwen's narrative was structured to portray this cycle. There was a strong consistency in Gwen's thoughts (e.g., frustration) regarding exercise over the year, and it was through the inclusion of repetition within the narratives that I aimed to portray these thoughts. The next sections will provide reflection on themes developed, body language and voice within the interviews, and narrative type over time.

6.2 Narrative one

Gwen's desire to keep physically fit was overwhelming. Within the first narrative, the one word that rang consistently throughout was "frustration." From the start of our interview, I heard, saw, and felt Gwen's immense frustration at her exercise restrictions caused by her uncontrolled seizures. During our interview, I could visually see the frustration in her face and body language. As I sat there listening, her words began to affect me, resulting in the frustration of my own exercise situation rising within me. Having to constantly keep myself in check, interviewing and analysing Gwen's interviews were the hardest aspects of this thesis.

The first story form became visible quite early on in the research process. Describing the "catch 22" early on within the narrative, it appeared that there was a cyclical nature to her narrative. The cycle began with Gwen's desire to stay fit, resulting in exercise. However, the common after-effect of high intensity exercise was a seizure, resulting in the prevention of further exercise until the side effects of the seizure improved. When exercise was prevented for a long period of time, Gwen's frustration would increase. This increase in frustration caused Gwen to compensate via a higher intensity or frequency of exercise for her missed exercise, which resulted in the occurrence of seizures. Then the cycle would begin again. This cyclical nature of her frustration was something that had not been yet shown within literature. As her story was not accurately portrayed within literature, e.g., Frank (1995) or Lieblich et al. (1998), I was intrigued by this new additional narrative type.

Describing her frustrations, Gwen seemed deeply upset by the fact that she desired to exercise consistently, yet could not. She seemed angry and at times defeated by this.

The idea that she was “missing out” and was “held back” by her seizures resonated strongly throughout this first narrative. The feeling of “missing out” was heightened by a sporty social support system. She desired to do what others could, yet was prevented by her epilepsy. This element added to her frustration, intensifying her emotional response. It seemed there were many layers and variables involved with Gwen’s narrative. Not only did she feel as if she was in an endless cycle of frustration, but there were also others around her doing what she physically could not.

Identity was another theme that was heightened from the start of Gwen’s narratives. Describing herself as sporty and identifying with being a sprinter at school, these thoughts sparked the concept of how her athletic identity has contributed to her emotional response. Her depiction of how much epilepsy encompassed her make-up was also interesting to note. Saying that she would not know who she was if she did not have epilepsy, confirmed that having epilepsy can be all encompassing. It seemed that having this identity of epilepsy may have conflicted with her athletic identity, increasing her frustration in regards to her lack/prevention of exercise.

Throughout this first interview, the sense of envy and frustration seemed to be threaded throughout. These feelings had not been shown before in epilepsy-related literature and excitement took over in being able to present these emotions. After this initial interview, I was eager to see how Gwen would maintain or change over the course of the year.

6.3 Narrative Two

Upon beginning our interview, Gwen looked physically very much the same, as well as seemed quite content. As we progressed, I was happy to hear about the changes

in her sporting habits, i.e., switching to swimming. This change seemed to have a strong affect on her view towards exercising with epilepsy and its benefits to her body.

Revealing her new choice of sport, the theme of ‘sport/exercise type’ drew attention to exercise type’s effect upon her emotional response to exercise (discussed more in the discussion chapter).

Swimming was found to be a benefit to Gwen. It seemed that swimming helped control her seizures, rather than hinder. Her sense of bodily control was heightened, control that was previously missing whilst going to the gym or running. She felt that she could push herself in the water, yet would not feel the negative side effects experienced when pushing herself at the gym. This sense of bodily control was very interesting. It seemed to tie in with the literature theme of ‘the body’ and its importance within illness and exercise (will be further discussed in the discussion chapter). Previously explaining that she felt her epilepsy controlled her body, it was exciting to see how her new sport choice of swimming caused her to gain a sense of bodily control.

The cyclical “catch 22” story continued throughout the second narrative. Not only did she maintain the belief that she should increase the frequency and intensity of her exercise, but now that she felt swimming was a better sport choice, she decided to increase it even more! As swimming had a relaxation effect for Gwen, she believed it had also resulted in fewer seizures. She did not deny that seizures were still occurring; however, the cycle seemed to shift. The cycle appeared to change through this adaptation, forming more into the shape of a corkscrew. Visually, I felt this could be seen as beginning to become more linear through times of bodily control and feeling the benefits of swimming, and then back into the cycle after pushing herself too much,

resulting in seizures and a sense of frustration. Although I did not gain a sense of a drastic change in the cycle, she was adamant that swimming had changed something. She was very excited to express this change to me and through her large gestures and smiling face, this came across quite strongly. However, with her reporting that seizure frequency was not dissipating, it seemed that this was more of a mental belief that swimming limited her seizures because of her increased bodily relaxation and control she now felt.

The concept of switching to swimming came as a bit of a shock. Immediately, I felt uneasy. I do not know if it was because there is such a taboo around swimming for SWE, or the fact that she wanted to push herself more still; this seemed to be a dangerous situation. Not knowing how to ask if she realised the danger without feeling like I was telling her off, I gently asked if she would tell the lifeguard or swim with anyone. The response was one that I often would tell myself. The belief that the lifeguards may “freak out” had been a deterrent for discussing a potential dangerous situation with the one figure that could make swimming safer. This made me think, why are we so against telling the lifeguard? Gwen seemed to feel like she was safe and that telling the lifeguard was not necessary. This brought to my attention the stigmatic relationship that epilepsy carries. As a hidden disorder, Gwen felt that her epilepsy does not have to be discussed until it appeared, despite the potentially life-threatening consequences. As a result of this new insight, hidden disorder became another staple theme throughout her narratives.

Hidden disorder was a theme that ran through each narrative, and its importance to creating or defining Gwen’s identity as well as having an impact on sporting life was

too important to ignore. Not only did her hidden disorder factor in safety concerns (whether or not the lifeguard is told), but also how others view her sporting routine. It seemed that through the hidden aspect of epilepsy, Gwen disregarded these concerns and continued on her own path irrespective of any other outside view.

From this second interview, I felt a strong change within Gwen. She seemed more excited regarding her exercise routine, and less frustrated. Gwen had found an exercise type that helped her body rather than hindered it. She did not deny that her seizures were still occurring; instead, she just explained how her feelings of relaxation whilst exercising had caused this slight positive change in her cycle. Viewing her vicious cycle as more of a corkscrew now, I was interested to see if there would be another transformation within the next three months.

6.4 Narrative three

From the outset of the interview, it seemed that the cyclical nature of her emotional response to exercise had returned. Uttering the words “vicious cycle,” it seemed that Gwen had appropriately named her narrative type. Interesting to note, describing this cycle within my own interests in exercise, I have also called it a “vicious cycle.” When Gwen used these words I felt a sinking sensation in my stomach, but also a surge of adrenaline at the same time. “Yes, that’s right!! I understand!!” However, realising these words were screaming in my head during the interview, I quickly had to take a step back to maintain my researcher stance.

Her cycle was visible through her repeated utterances of frustration and she seemed to have retreated from her energy and excitement of the last interview. It seemed

the newness of the choice to swim compared to running had worn off. Gwen discussed the negative emotional effect of the realisation that although she may feel a bit more in control of her body, she still did not have complete control. This emotional response emerged from her facial expressions, body posture, as well as her words. Although the initial feelings of frustration were evident, she did discuss a moment that caused her to re-think her exercise routine.

One point that struck me during our interview, was hearing that she had swam after having a seizure. Although not immediately after her seizure, it seemed as though she wanted to give swimming a try and take that risk, hoping for the best. Her excitement that she remained seizure-free after this post-seizure trial was fantastic. I felt her joy of finally being able to not be prevented to exercise by her body, even if it was just one swim. She discussed how the cycle of frustration changed again with this latest decision. Focusing on how vicious the cycle was, and how it can feel like endless continuity, she felt very happy to have broken the cycle this one time. However, the unpredictability of it remains. She may have this one instance, and then try it again another time, but not be as lucky. Those are the decision-making processes that need to be discussed. What made her not have another seizure this time? She did not know, I do not know. But not knowing how to decide for the future also added to her frustration. I was happy to hear her discuss that it does have to be a smart decision, i.e., one must listen to their body. She recognised it cannot be a, “no matter what” decision. She felt good enough to go, and she went. The result was a feeling of strength and bodily health.

In this instance, she did not feel physically unhealthy; however, she stated that she would not have gone had she felt differently. As she told me this, I felt a feeling of

calmness come over me. This seemed to be a change of attitude towards her decision-making process. She later discussed her feeling of exercise progression through listening to her body for signs of being able to exercise, versus a day that she should restrain. She discussed that she was physically different than people who did not have epilepsy, and therefore she must adapt her exercise routine. She did not like this very much, but by the end of this third interview, I felt there was a slight mental change towards the positive in regards to adaptation and acceptance. I came away thinking she seemed more accepting of her body and exercising with her seizures. Within her storied form, this increased acceptance continued to morph the vicious cycle into a more constructive linear nature at these points of acceptance and adaptation, and then returning to cyclical in moments of increased frustration, thus continuing the corkscrew shape.

The theme of hidden disorder was maintained throughout this narrative. She mentioned her hidden disorder, yet these were similar identity-making statements that she had stated in earlier narratives. I felt that including these would allow the reader to see the same mental formation of her identity was threaded through the narratives over time.

As a result of this interview, not only did I fear Gwen's decision to exercise on a seizure day, but it made me think what would happen if one day she would try again, but with a different outcome? However, I also realised that these 'what ifs' can create fear, and this fear will not help any SWE to exercise. By not taking risks to beat this fear, maybe her cycle would have remained in an unending circular pattern.

6.5 Narrative four

Gwen's final interview was split into two sessions. Having limited time the first session, I felt rushed and tried not to let it affect my ability to ask questions nor the importance that even a shortened session can have. From the beginning, I was already intrigued by her becoming embarrassed and whispering when she discussed her epilepsy. The hotel lobby where we usually meet seemed quite busy today, and I could see her insecurity of wanting to stay hidden.

Gwen's vicious cycle had continued. She seemed down and not as excitable as she had been in the last two interviews. Frustration remained and was heightened by different triggers. Her husband's ability to exercise consistently and the increase in her seizure frequency seemed to start-off the cycle again. She discussed her frustration as she did in the first interview, one year ago. It seemed that the good days made the bad days even worse. Confusion, anger, and frustration seemed to arise within Gwen as she discussed how one day she could be fine after a seizure, and the next have numerous seizures, although it was the same amount of exercise. She seemed really down and I got a sense that this feeling of her lack of control had increased again. Discussing her reasoning for frustration, Gwen became very impassioned by the inability to train for any sport. This idea of the inability to train for an exercise goal frustrated her immensely. It was not that she did not have the motivation and desire to, her body just would not let her.

An interesting aspect of this interview was the occurrence of contradictions from previous interviews. Stating that she never would exercise after a seizure, she seemed to not remember that this had occurred before. After drawing this to her attention she

stated, “I may have done. I may have done. I’m very worried about that. It’s very rare.” The effect of her poor memory had caused her to forget that she had this occurrence of swimming after a seizure. Had she remembered, maybe her fear would lessen and this may have occurred more often.

Within this last interview, Gwen continued to portray her ability to increasingly listen to her body. Exhibiting continued adaptation methods and an increased acceptance of her bodily limits, the semi-cyclical or corkscrew nature of her narrative portrayed these changes or extensions of ‘normality’ until it returned once again into the cycle. Finding yoga and tai chi to be relaxing, she benefitted from a source of exercise, yet also decreased any stress levels that could trigger seizures. I was very happy to see that she was not giving up and recognized new sport/exercise choices to gain that “relaxation feeling” created by exercise. This increase in different exercises and postponing of exercise was because she recognised she had to listen to her body and acknowledge any physical limitations. As frustrating as it may be for her to admit to limitations, I was happy to hear this continued, and also increased as time went on. I felt she was learning how to exercise safely and more effectively through verbalising her frustrations to me over the year. She was growing, and although there were setbacks, I felt she was learning from her experiences.

Discussing her identity, Gwen told me that she does benefit from having epilepsy. Although maintaining her hidden disorder identity in regards to sport and work life, she also felt that epilepsy made her a more determined person. I could see she was very determined. A practicing psychologist, she was now going on to do her PhD part-time as well as full-time work. When she said it makes her more determined, my heart

jumped, as I had felt the same. We then got into a conversation about how epilepsy has changed our lives not just for the worse, but for the better. Gwen portrayed the sense that she does not like being told she cannot do something, hence the increased determination to succeed. Although this was beneficial in most of her life, when it came to exercise, this was one of the causes of her frustration with her body. She did not want to be controlled and told “no” by her body, yet she did not seem capable of making that decision within the exercise arena. Her body tells her what to do.

6.6 Concluding thoughts

Gwen’s narrative was one of the most challenging to edit and form. Her repetitions, memory lapses, and contradictions caused doubts in how best to portray her story. Many edits, re-reads, and communication with Gwen confirmed an accurate portrayal of her story type. I was very taken by Gwen’s story. Not only was it very similar to my own, but the way her cycle unfolded seemed to change within every interview. This was only one year of her life. One discussion, every 3 months. What happens in the future? How else could it change? Although there were setbacks over the year, Gwen communicated her cyclical story of frustration and learning to accept to exercise with epilepsy. At the end of the year’s documentation, forming more of a corkscrew than a circle, the vicious cycle changed from the constant cyclical nature of how it began. Although frustration may continue, the adaptations in sport type and moments of acceptance seemed to positively benefit Gwen’s psychological state.

7.0 Maya's narrative

7.1 First narrative

See for me I'm invincible, that's what I believe, you know? ... I just kinda think nothing will happen to me and nothing will happen to me. I put myself in REALLY dangerous positions and nothing has ever happened to me. So, I'll continue like that through life until something does.

The fact is I want to be the first person who has epilepsy that will swim (the English Channel)... I've got two years, I booked my solo... And, umm I realised now how much it takes. I have to put on two stone... I'm not going to put on two stone. It's not going to happen! I'm okay with putting on a stone, to a point! I don't want to put on any weight. And I was asking, "Has anyone swum the Channel without any fat on them?" There's been a few, but they've been complete nutters... But, they're saying, however much your mindset is, hyperthermia will just take over, whether you want it to or not, after about 10 hours. I'm hoping to do the channel in less than 10 hours so it doesn't... There was a race in Dover, it was open water, so you couldn't wear a wet suit. I thought, "Ok, let's beat it, let's get there!" I got out after half an hour. You can feel your bones, you're so cold. And I was like, "My god... I'm not strong, I need to get better."... But I'm so competitive, that I want to wear a wetsuit so I have a chance of winning! ... I did a race without a wetsuit and I came 20th! It was out of about 1000, but that's not the point. I didn't like that... It's something I need to get over. There's still loads from up here (pointing to head). I've noticed there are loads wrong. When I'm swimming the channel, and I'm standing at Dover, I will be ready. I will be so mentally healthy, it will be incredible.

I've trained a lot as a child. Up until the age of 18, I trained every day. And then I had, then I got an eating disorder from going onto Topiramate¹⁵. It takes your appetite away. And I lost loads of weight, lost loads of muscle, and couldn't swim. And then I didn't like the idea of putting on weight, so I kept it that way. Then I went to Uni and got better. Tried swimming again and then got very serious last year, and then seizures all started again. So, maybe there's a connection. But I think my body, maybe everything's changing in it. Cause I was a competitive swimmer for 16 years, and now I'm competitive again and I have loads of problems. I think epilepsy has a connection with swimming as well. I don't know, I've had one fit while I was in the pool. That was fine, and then I just continued on swimming.

Sometimes I think mentally you can control it anyway. Cause I think sometimes with my fits, I might go like, I might feel it. Other times I'm not, I might just ignore it and don't concentrate on it and therefore it's not, I can't feel it as much. My mind is pre-occupied with something else. I don't know... I kinda swam through mine, I was kinda just a little bit... blind... Yeah, but I had to stop; I couldn't see where I was going. So I did stop, wait for it to finish and then carry on. So that was the first time I've ever had a fit whilst doing sport.

I went onto a long distance camp in March, and they didn't push me because they were scared of me fitting, and I had to do loads of medical things to let me go... But, you know, I thought I was a strong person, cause of the shit I've been through. But I haven't really been through stuff competitively, it's been epilepsy. But you'd think you're strong when you're tired and you get up and you go training, and you do what

¹⁵ AED

you've got to do, even though drugs might stop you from doing everything. And I wasn't strong at all.

On holiday, I had one fit. I got back, and I had about 10. I don't know if it was a result of it, cause we were swimming about 10-20K a day. And umm, it hurt, it hurt. (laughs) I started training really properly, so much that people started asking, "What you training for?" "Not much." Not much really, cause I'm not swimming the channel for two years. I'm just trying to keep it at a pace that when 2013 happens, I can pick it up. It should be interesting. I have a 14K coming up and a 10K and a 5K and a 3.8. And I'm going to do every single one without a wetsuit. The only one I'm worried about is the 14K because it's about 4 hours in about 15, 16 degrees. And I kinda blagged my way on it saying, "I've done loads like that." I haven't done any! 'Cause they have all these swims that you have to do for the channel, that are 6 hours. And the most I've managed to go to is about two. SO I have a long way to go and I don't like that sort of thing.

You know, these people who have to do with the Channel Swimming Association, they always have a fear of, umm, my connection with water, because they don't want to be held responsible. But I don't think there is any connection between the cold and my epilepsy, because there is a connection between the heat. The fact is I want to be the first person who has epilepsy that will swim the Channel. But Professor M¹⁶ said, "I will be the first epileptic to die swimming it!" ... I don't think I'm going to die swimming it, you know... Just because epileptics shouldn't swim the Channel... But it's going to take a lot to convince them. If I was 2 years clear (seizure-free), I think it would be quite easy. But I think because I'm still early days, not even 24 hours, really, I was

¹⁶ Pseudonym for her neurologist

hoping I wouldn't even have to tell them, but they won't insure you and they look at your medical records. It's just annoying that they're not helping me out, they're making it harder. They shouldn't be. They should just ... a lot of people get scared when they hear that word....

I just think it's because they think epileptics shouldn't do stuff like that. Because epilepsy's stress-related, surely the channel's going to be stress-related. People with no limbs have swum the Channel, people with diabetes have swum the Channel, I've never heard of an epileptic swimmer. Maybe someone who used to have epilepsy? But I don't see how it could affect me. I've never, up until 2 weeks ago, I've never had a fit whilst doing sport. Then I did, which was really random, but I just swam through it. Got out, got it finished, got back in.

I only have fits when I acknowledge my tiredness, when I relax. When I'm sitting at night, or watching TV, when I've calmed down. That is the only time I have fits. Never during the adrenaline, never during the fight or whatever. It's always when I'm chilled or overwhelmed. I don't think swimming the channel will be a problem, unless I get hyperthermia.

I'd be screwed if I had one in the open water, to be fair. I'd be absolutely screwed. Because I don't lose feeling as such, but I lose concentration. And it's almost like, lactic acid build-up, and you've got lactic acid, so you can't actually feel anything anyway. You're just swimming, hoping you're moving. It would be like that, but not being able to move. It will be like cramping up, but a different pain. And obviously, in open water, you do have, kayaks, the whole way. But in some races there's been 2000

people, a kayaker can't keep up. To be fair, they always do keep an eye on us, 'cause there's always ten of us that don't wear wetsuits... The only problem with the channel is, when the waves get more than 2 meters high, if I had one, I would drown. Because you'd just take in too much water, you wouldn't be able to get on top of it. But, I don't see that ever happening, I don't see that happening. I don't think it could happen while I'm swimming. I'm going to build the distances up before I get there, so do other swims that aren't as long, but will put you in the same sort of climate for 10-12 hours. If I don't have one then, then I'll never have one! I don't see ... it's in the mind. If I don't let myself relax, then I'll never have one. It's when you get on the boat, and you're like, "Ahh," (sighing sound) and then I'll have one... As long as I keep tense and a kind of positive frame of mind or whatever, then I won't have one

Nothing will stop me. Sometimes I think it's OK, but if I'm REALLY tired, if I haven't eaten that much that day, I won't go swimming. I think it's OK, but I have to make up for that. No, nothing will stop me unless I'm really ill. Like flu or something, that's about it... I'm coming from no cold water training and that's why I'm so crap. So I'd like to see out what actually it would be like. But I've been at my worst and it hasn't affected my epilepsy. I've been at that sort of pain which you cannot imagine and you have to get out, and you kind of cope. 'Cause I like to think I can always push myself. But I know, I only get out if I can't push myself any longer.

I'm not very safety conscious; I kinda think I can do anything. I think if I had grand mal, I might be a bit more cautious, but because, my mum even said I used to make my fits up. She's brought me up with that kind of, "You're a hypochondriac" kind of thing. So when I was a younger, they thought I was making things up... I still have

this doubt now that sometimes. I'm just like, "You're not half as bad as this, shut up! You shouldn't tell people you're epileptic because you are so UNepileptic!"... But then that's because my mother. You know, the self doubt.

I wouldn't try as hard. I like it in a way, that it (epilepsy) makes me different, and everyone wants to be different, don't they? But, it also gives me a lot of eagerness to do stuff... I don't know, it reminds me that I'm epileptic every time I have a fit. This is why I'm taking drugs, there you go. I'm not a hypochondriac, I do have something wrong with me... It doesn't define me as part of me, but I just think epilepsy is not a big deal...

I'd say I'm doing more swimming now than I've done in my life, but that's not true because I am swam more when I was younger. But, it affects me more now than it's ever done. I feel it now, swimming. Yeah, I feel it now, the tiredness. 'Cause when I was younger, I was just born into a sporty family; you do sport. And then I went off it for about 4 years, 4 years of not doing excessive sport, just doing climbing, and going to the gym, and generally just looking very skinny. And then got back into proper sport again. I think combination of that and a full-time job. Getting up at 6, going to work, thankfully schools finish at 3, get to the pool at 4, swim till 5:30, get home, eat till 7:30, then go to bed.

They (seizures) make me tired. But I ignore that and go swimming anyway, and I then find it really hard to get home. We had a race, and I'd stayed at a mate's in London, didn't get any sleep. Got up at 5 in the morning, made my way to this race that started at seven, swam it, did all right, but then I couldn't get home! And all I said to myself was,

“One foot in front of the other, one foot in front of the other.” It took me three hours to get home!... I hated that, I absolutely hated that. I hate that I can’t just drive and just get home. The same from swimming... If I could get to swimming events on my own... But I don’t, I have to rely on everyone. It takes a lot of driving, I rely on my housemate Mark¹⁷ a lot to take me to the beach and training (laughs). He’s driving me about, and I always have to rely on people...

It’s going to be interesting to put myself in certain situations and try to push myself a little further. That’s why I’m doing this 14 K. It’s going to be quite warm, and I’ve asked permission to do it, and they’ve said, “Yes.” They don’t know I’m epileptic, so it will be fine. Mark’s going to be cycling ... Just for some extra provisions, ’cause if you’re doing it without a wetsuit, you have to bring someone extra to keep an eye on you. It’s going to be 14K, so it’s should take, 4, 3-4 hours. It should be interesting, should be fun. Should be good...

7.2 Three months later- Second narrative

I don’t really have a problem with the epilepsy, I mean, it annoys me that no one cares... It’s really annoying as well when you have the least amount of epilepsy, in the form of a fit. That, you can’t, you don’t even feel confident enough to say that you have epilepsy because it’s almost, you feel like you’re being a hypochondriac... They’re pretty much non-existent. And that’s what simple partial means, I basically have the same ones you do, but I don’t blank out.

¹⁷ Pseudonym

That's what annoys me. I think if it was grand mal or even complex partial, I'd get some acknowledgement... 'Cause it's simple, I might as well not have it, for all the help it gets. I'm there the whole time... But I do question, "Is this epilepsy?" But no one goes through their day and then they get this minute of pure agony. That doesn't happen to people, it is a seizure. 'Cause sometime I question, "Is it a seizure? Do I have epilepsy? Is that what epilepsy is?" Say we are talking now and suddenly I get this whoosh of absolute agony in my head, as an emotion. And it's so disgusting and makes me feel really ill and a sense of sadness. It's horrible, it's powerful. That's not normal, that's not what normal people get, that is a fit. And I know I've been diagnosed with epilepsy, so I know it is.

When I told complete strangers I'm swimming the Channel, I always tell them I have epilepsy, straight away. I don't know why. Must be some self-gratitude sort of thing. "Oh I'm going to be the first epileptic to swim the Channel." I was talking to this guy about my training, and how I'm going to be able to get to my training. And he's all, "How 'bout you learn to drive?", and I go, "I can't, I have epilepsy." And he's all, "Oh my god, I'm so sorry!" (laughs) I love that reaction, I love that reaction. 'Cause when they try to put you down as being lazy and you come back with that! ... I like to see how far I can go without telling them, so that means it takes away the pressure of not being stressed about it.

My epilepsy doesn't really affect my swimming. So I'm seeing how far I can get with that. I think mine gets affected from other things. I don't know... But then whenever I stop... I've been close, a lot recently... I did a week where I was really stupid, (little laugh) I did two races back-to-back. A 5K and a 14K, and that resulted in

three seizures. Seizures the next day, all in the matter of, like, 24 hours... I had a week off and then it was quite easy training, although that was a big session. (talking as she's showing me her workout and seizure diary) And then I got ill... again... and again... So... 2 days, 4 days, 5 days after the 14K I got really ill for a week. And then I swam for a week and got really ill again. (laughs) ...Yeah, now I've got better since the season stopped.

It tends to be the long, 14K weeks that I end up having seizures. Whereas I've had to cut back, to fit in my Masters, and make sure I do 9K a week. So whereas, in the beginning, I was doing like 20 K, 18K, 15K. And now I'm 9, 6, 3, 6, 9, 7, 5... But that's really 'cause I don't have the time to do the reading and the work and swim... I kind of put my swimming before my masters. I need to start; I get really edgy if I don't swim. I get really frustrated.

Do I train with people? On the currents I do, in the summers I do. On the weekends, I go to lakes and beaches with a training partner. He's swimming the channel on the same day I'm swimming the channel. He doesn't know, but I'm going to turn it into a race... I think if I train better, I have it in me to finish. I know, right now it's the cold. I can beat sickness and pain and all that. I know I can by those 10Ks. I'm in agony, but I still... But it's the cold that's a problem. Over the summer I always train with someone. Over the winter, I always train on my own, in the pool. Because I go at regular times, I sometimes meet people. Some of us, keep each other going. Everyone's always like, "Who do you train for? Who do you train with? What club?" "On my own. I'm by myself." People are shocked. But I don't want to pay any more money to do what I want to do. Only problem is, in a club, you have a dedicated lane that's not too crowded or

full of dickheads! ... Swimming's my thing, you don't stop me. I don't swim with friends. I don't talk, I just swim...

Swimming is not a sociable sport, swimming is where I live. I'm awake, I'm calm, I'm not thinking of anything, but the lengths, the number of breaths, you know? I love swimming. I've never been so obsessed with swimming in my life. I love it. Maybe because I have an aim. And I will always have an aim. Like after the channel, I'll just do another one, like the Irish Sea, or the Caspian Channel, or Gibraltar Straits, or Africa to the other continent, you know there's loads of swims. I want to be the greatest open water swimmer ever! ... The only time I'm awake is when I'm swimming.

The first race I came 64th and the last one I did, I came first. That shows the progression... I'd love to be in team GB, but I need to I think, massively, 'cause I want to break some records first. Not trying this year, but next year.

I would have just done more if I wasn't epileptic... Some of the things I wouldn't do if I was not epileptic, I wouldn't have achieved so much academically. 'Cause I wouldn't have brain damage, and I wouldn't have to fight everything. And doing my masters full-time. It's saying, "I'm epileptic and I don't give a shit." People say, "What are you trying to prove?" The trouble is nothing. If someone can achieve greatness, so can I. I'm great, and I can do it.

7.3 Three months later- Third narrative

In my life, I've probably had two in the water. Two when I'm swimming, I just swim through them really. Go to the end, wait till they finish, and carry on. (laughs) 'Cause this is it, I know what they are, they're auras... Like with swimming, I wouldn't

tumble turn. But I'd carry on swimming because it's so natural to me, swimming... If someone needs to concentrate, I can't concentrate. But swimming is not concentrating for me. I know how to swim. It's like I know how to talk. Like if I was writing an essay, I'd have to stop. If I was holding a glass, I'd have to stop... I definitely don't think it affects my sport. I think, I think as you build-up, like professional athletes, well, this is my theory. As you build-up sport, your body relates to that sport, and it relates to that health. It's not enduring it. It's not like someone really unhealthy goes to the gym for 5 hours and has a seizure. I think that's a real stressful thing... 'Cause as you build up, your body goes with it, and your health goes with it. The more sport I do, the healthier I am... That's why I'm not sure about my swim. I'm going to have to be overly trained for it. 'Cause if I'm under-trained, any sport, extra, will affect me.

When I have less seizures, there's more swimming. So I've swum 36K so far this month and had three seizures. 33K last month, four seizures. 23, five seizures. 13, six seizures. The less I swim, the more fits I have. That was when I started my job. 30K, one seizure. That was before I started my job. My neurologist thinks my drugs have stopped working. He wants to double my dose. 31K, one seizure... I don't think there's any such connection really. I don't know, once I start picking up, I think it will be interesting meeting up in, umm, August, or July, once I start training up to 40K a week, instead of 40 a month. That would be interesting. At the moment I'm not putting any strain on my body. What I'm swimming would be a strain for someone who doesn't swim, but isn't a strain for a swimmer. It's more than I did last year. Last year I did 1K sessions. Or even the year before, you know, 1K was MASSIVE! Now 1K is my warm-

up! I think, as I build up to it and my body gets used to it, it's no strain on my body whatsoever... So, it is the more I swim, the less I had seizures.

Having a seizure while swimming, doesn't cross my mind. No, I only think of them when I have one. I don't think about having them any other time. The only thing I think about before swimming, is what set to do and how to make something more interesting and how much time I've got... So my swimming isn't very strenuous, it's just non-stop. It's getting quite tedious really. I'm just trying to go 3K non-stop and then do a further K. I've got this training camp next Saturday... And I should be doing 5K everyday at the moment. I'm doing like 3K, every other day. (little laugh) But last year I didn't do any training, and the fitness was fine, it was the cold. I'm sure I'll be better. I don't think I'll achieve what I want to achieve, but I'm sure I'll be better than last year...

I'm finding it, the difference is it's flowing a lot more. There's instances when I enjoy it! (laughs) Whereas before I was just trying to get the swim done. Whereas now I'm really flowing, and I'm trying to get my breathing strong and... I love racing, I'm really, really competitive.

I'm competing a bit this year; I'm going to compete in a couple of races. Like last year I did 20, this year I did two... just because I've got this swim (Jersey). I'm not concentrating on racing, you know, I'm concentrating on distance... If there's any interesting swims, then I might do it.

If I drove, I'd go the lakes... I'm just worried 'cause I don't drive. I mean this training has got to be like climbing Mount Everest. It's got to be proper, and it's not at

the moment. It's not even club standard, it's just swimming more than anybody. Yeah, I know the training plans, it's just getting the time to do it.

I'm always tired... I know if I slept, and I'm not tired, I can do anything! But when I'm tired, I can't do anything... See, I can swim in any condition. But I do notice, when I'm stupidly tired, I find it very, very hard. And I almost convince myself, "Maya, it's ok." And I do stop myself when it's that bad. But I do feel really guilty. But there's no point doing an easy session if it doesn't make any difference. Might as well get my sleep and do a harder session the next day. Like yesterday was a VERY easy session, 2K, is not really acceptable. It's better than a kick in the face. It's only because I knew I wouldn't be able to swim today. I'll swim tomorrow. I finish work at 2. So I'll swim for a good 2 hours and then work...

Umm, I'm going to get sponsors for the channel, after I've swum Jersey. But I don't want to organize sponsors and then find out I can't swim it because of health restrictions, or anything else... And I don't want to claim disability benefits because I'm trying to get medicals passed, you know for my swimming. Like, if they then see you're bad enough to get disability, they'll probably say, "No." You know? That's not, that's not great.

My goal is GB triathlon and I was thinking, because they want to get elite swimmers into triathlon and I like the idea of it... I don't know. I've never heard of an epileptic swimming the Channel. I would have think they'd let it known. I know diabetics have done it. I want to be the first.

7.4 Four months later- Final narrative

Yours is really related to sport. Whereas I think mine is related to being shattered, being stressed. And what I did on Saturday, I've never taken my body to that extreme. It was pretty obvious that I was going to have one. Alright sure, I didn't take my meds. But usually I can go months without taking my meds. But obviously one morning session, if I've missed my meds, I pretty much have them (seizures). But I don't think, for me, there's a direct connection. You think, in general, stress, tiredness, equals sport, equals epilepsy. Pretty standard. My body is used to that sort of sport. Especially training sessions. It's not used to, wasn't used to it on Saturday. But even my 6 hour swim, my training camp, which is pushing my body to a new extreme, I had a seizure the next day. I did, I did. I had three actually.

They're not connected, for me. Yeah, the next day, I get it. Yes, but I can never see if that's just because you push your body to extremes and anybody's going to get affected. OR, if I have forgotten to take my meds. 'Cause normally if I get up for an extreme race, you get up at 5 in the morning and I don't like to put anything in my body at 5 in the morning. So I don't know the connection. Whenever I have gone to the extremes, I've always had a seizure the next day... not during. (yawns)... When I'm swimming I'm fine. But then it's the getting home... I don't have them during. I've only had one during, and that was a swim down. You know, that was an easy swim, that's probably why I had one, 'cause I wasn't focused... I have it on a come down, not up. The thing is, swimming isn't adrenaline. It's not like a marathon when you get adrenaline or extreme sports, open water you don't get adrenaline to keep you going. I find that when I'm in the zone, I won't have one... It's when you come out of the zone,

and acknowledge, “I’m pretty tired”... that’s pretty dangerous, acknowledging. Umm, ’cause my brain says, “It is ok, you’re tired, have a fit.”

When I swim, I think about being tired. I mean, my body is fit and I think, there’s no way on earth this is sensible, when you’re freezing and never recovered from the 3 mile. But I said, “It’s only two laps, all you’ve got to do is move. Doesn’t matter if you can’t feel it, you know you’ll get round.”... There’s been times where you can’t go on, but you know you have to just remind yourself that in 10 minutes you’ll be fine.

No, it doesn’t bother me. I mean I know I’m going to have one the next day. But it doesn’t... what pisses me off about my epilepsy is the tiredness and the restriction in knowledge and remembering. Jobs and... the general lack of acknowledgement from other people that can’t understand why you’re tired. That, even though they’ve seen you have a seizure, they go, “You’re such a hypochondriac.” And uh, and people saw me have them and said, “That’s not epilepsy.” I just want to punch people in the face when they say that. ’Cause I have to stop, because they hurt. It’s more what they do afterwards, the long-term effect, than just what they are. But so many people have said that to me, throughout my life, that I am convincing myself, that I don’t have epilepsy. That it’s just a weird thing, that isn’t epilepsy. But other people don’t have it. They don’t have these moments of pure agony that stops them in their tracks. They don’t have it and they don’t fall asleep all the time, and they can read an article within an hour, and take it in... But the people without epilepsy never have those moments. They just live their lives, everyday, they might get tired and that’s it!... So you think, actually, I am. I have got this thing... They don’t understand the difference between our brains and their

brains... that's what annoys me about the epilepsy. Not the swimming. I do the swimming because of it. My work life and school life are massively affected.

Umm, it's not really an issue. If I have a seizure during the swim, there's nothing they (others) can do. Yeah... umm, but swimming, my mum is a bit worried. I say a bit worried, she's seen me in a state before. We went open water in the lake, and I've just come back from flu, and even though it was 14 degrees, that's pretty, pretty standard, I got so cold. And I was absolutely vibrating, absolutely shaking, which is a good sign. And I had to down hot chocolate and get completely dry, really, really quickly. And she was like, "Shit," you know, "Why do you do this?" That's pretty normal. That's pretty, that happens all the time. So she saw what happens to my body, and starting getting slightly worried. And even if that wasn't that bad, she said, "What happens if you have one while you swim?" I won't. I very much doubt it, I very much doubt it.

But I've worked out I can mentally do anything without even training. Say, like what happened on Saturday was done on not much training. I'm meant to be swimming about 20-25K a week. Fuck that! At the moment, it's probably about 15 K. But, what I've noticed, it doesn't really matter for me.

I'm thinking I'm going to have to get fitter. But I'm back on it. I mean the last week; I've been enjoying swimming again... I've stopped keeping a diary, umm, of my swims; just keep one with the seizures. 'Cause I know what I'm doing and I know if I haven't swam for a day, I NEED to swim!... But I've gone back to swimming Monday, Wednesday, Friday. But I shouldn't be, I should be swimming, Monday, Tuesday,

Wednesday, Thursday, Friday. It's fine, I mean, it's ongoing... It's going to pick up, it's going to pick up... And then the seizures are probably going to go down.

Open water swimming isn't about swimming as such, it's about the mental thing. It's about the endurance; it's about dealing with the cold, dealing with salt water, dealing with swimming for 6 hours, about dealing with the vomiting reflex.... that's what open water swimming's about... At the moment it's all about mental challenges. But I think it's making me a better person, in my head. Compared to last year, the fact that I'm managing to do more swims now, I must be more secure in my head.

But nothing will ever stop me. Maybe grand mal, but I will never have grand mal. Nothing will ever stop me, whether it's connected or not. I think I've ruined your study really. There is obviously a connection with any form of epilepsy and pushing your body to the extreme. It's obvious that you're going to have a fit...

Do I have any limits? Not yet, haven't found out yet. Saturday was my biggest challenge. Yeah, and umm, even though it was less than I've done before, and I had a seizure the next day, but it's not a big deal to me anyway. I mean, eventually I will need to control that, but umm, obviously I wouldn't do a sport like mountain climbing.

I think that's why I do these things, to prove I have no limits. I mean, if other people can do it, I can do it. You know? ... But if these normal people, bankers and teachers, everyone can swim the channel and push their mind to that extreme, I can! People with diabetes have done it. People with no legs have done it! ... I can. No, I don't think I have limits. I think I'll always have seizures while doing it. As long as I'm an

open water swimmer, I'm going to have epilepsy. But I'm never not going to be an open water swimmer, so...

8.0 Maya narrative summary and reflection

Maya's narrative portrays an athlete whose exercise goal and routine was not favourably looked upon in elements of society. Being an open-water swimmer, I felt that her inclusion within this research was important and may bring up questions in regards to safety and exercise inclusion for SWE. Although interesting to talk to, Maya was a difficult participant to interview. Contradictory in many of her statements, she seemed in a constant state of denial and would often get off topic. Maintaining my stance as researcher, I had to reel her in every now and again and find ways to get her back on the topic of exercise. The contradictions as well as my own worries and strategies as a researcher will be discussed within this chapter.

Maya's narrative type seemed harder to discover than the other participants. Concluding that her narrative over time was shown to be a steady narrative (Lieblich et al., 1998), the following will discuss the elements that portrayed this narrative type. This chapter will examine Maya's narrative in regards to effect over time, followed by a discussion of each narrative in regards to emerging themes and narrative type. Researcher reflections will be threaded throughout to provide more insight into how and why such conclusions were made.

8.1 Narrative over time

Witnessing the year's narrative, I felt that time was not as strong a factor within Maya's story as compared to the other participants. She seemed to stay quite consistent in her mindset that her epilepsy was not affected by her exercise, as well as within her opinions on other's reactions, exercise routine, and emotional response or lack thereof.

This was interesting as there seemed to be many reasons why she was so consistent. My first thought was that because, out of all the participants, she has had epilepsy the longest. Maybe since she knew the cause of her seizures (a brain tumour initially, and now scar tissue), that she felt that there was no cause for concern regarding exercise. I do not know the answer, although Maya thought this has to do with how she was brought up as a hypochondriac. No one took her seizures seriously, so why should she? This was the resultant view of how she approached her epilepsy.

Viewing a SWE with a consistent exercise routine, regardless of seizures was quite a change. Yes, there were times when she could not exercise, yet it seemed that she was quite stable in maintaining her exercise goals. Her strong athletic identity and goal of swimming the English Channel may have been the reason for maintaining a consistent exercise routine. Interviewing a participant who stayed constant over time, it is of interest to point out the variables within her story to conclude why this might be the case. Her consistency has allowed another side of exercising with epilepsy to be portrayed that has yet to be shown within research.

8.2 Narrative one

From our first meeting, I realised Maya would have a different story to tell. At times, she would talk so fast or switch from one subject to the other, with no similar theme, that I thought I would not be able to cope with interviewing her. I had to try hard to follow and made sure I stayed in charge of the interview as a researcher. Maya was not shy, nor embarrassed to tell people about her epilepsy; I was amazed at how confident she was within her own self-identity. She knew what she wanted to do with

life, and epilepsy was just this annoying thing on the side. It did not stop her from swimming, achieving her goals, nor did it even factor in as a safety measure. One of the early examples of this was her discussion on swimming through a seizure. Fear immediately struck me. “What do you mean you swam through it?” I couldn’t believe it. Thinking that her seizures are not bad enough to worry about, this nonchalant attitude to her epilepsy was refreshing, yet also worrisome. Her disregard for her own safety made me wonder, how she has yet to injure herself? I believe that it was not just carelessness, but confidence, denial, and high self-esteem that created this persona. Upon hearing this statement, I was confused how she could state that there is a connection with her swimming and seizure frequency, and then later state her swimming does not affect her seizures. I was left wondering how this could be the case and upon clarification, did not feel that she realised she had made this statement earlier. Listening to her transcript again, I realised that even though I tried to get more clarity with her conflicting statements, it was quite hard to always achieve this. She would just re-state that there is no effect, yet not justify why she said there was an effect earlier. This was an ongoing occurrence and made re-reading and analysing difficult to ascertain exactly what was her position on the subject.

Maintaining a strong athletic identity, the goal of swimming the Channel was quite awe-inspiring. Although it was early days with her training, she seemed to be quite confident that nothing would stop her, and I believed her. She seemed to have no hesitancy, and discussed more the issues of dealing with the cold water than possibilities of having a seizure in the open ocean. Having a strong mental attitude helped her continue swimming even though tired, or maintain her routine whilst juggling a

work/studies workload. I was happy to see such a strong minded individual and how she used this to maintain her sporting habits. She even discussed the positives of having epilepsy as this has made her mentally tough. Such a statement was seen within the other participants as well and when she stated this, the same feeling resounded within me.

Social support was a topic that seemed to create discontent for Maya. Not only did she discuss her issues with convincing people she had a definite disorder, but convincing outside medical professionals or officials within the sport that she was fit enough to swim. This seemed quite frustrating for Maya, and she became very passionate about these barriers to overcome. Not only was she doing this swim to prove to herself that she can do it no matter what, but I think also to prove to others. She wanted to show the world that people should not be scared when they hear the word “epilepsy,” but be accepting.

Discussing her epilepsy identity within everyday life, she was not hidden. She proudly stated she had epilepsy to whoever would listen. It seemed to me, as she described how she told others, the reasons to discuss her epilepsy were to scare people or test their reactions. It was not only because she was proud of who she was, she wanted to assess others on their judgements or stigmatized feelings. This seemed a bit odd to me, yet I accepted that her strong identity caused her to feel that others need not to be scared. Although she was very open with her epilepsy in everyday life, in terms of her swimming, this does not always occur. Not consistently disclosing her epilepsy to officials in case they do not let her swim, she realised the stigmatic effect. As a result, she decided that she would rather swim than be judged or prevented because some

people were scared for her safety. I thought this contradiction was quite key to Maya's story. I was interested to see if this would change as time went on and it became closer to the time of the swim.

Maya's story did not seem to fit a narrative type and I could not put a finger on her story structure. Comparing her to Frank (1995), she did not quite settle within any of the storied structures shown. In terms of visual structure, I felt she was a plateau, or baseline, neither went up nor came down. This would be similar to Lieblich et al.'s (1998) the steady narrative. She was the most consistent participant in terms of maintaining sport habits as well as eagerness to ignore any medical orders in regards to her safety whilst swimming. Although she realised the dangers of what she was doing, she did not believe that she was in danger. Stating that "It will never happen to me," her stubbornness or denial to not acknowledge epilepsy's effect upon her sporting life maintained this storyline's steady shape. However, there were little hiccups that seemed to cause anger and frustration at her maintaining her sporting routine. Not being able to drive, as well as having to make-up for lost time because of seizures, seem to point to a future possible change in narrative type to a more 'roller coaster' design.

Although a feeling of uncertainty always overcame me whilst talking to Maya, I was also quite amazed at how confident she was. Happy to see such a confident and vibrant SWE, I wanted to maintain these interviews over the year and see if she ever changed.

8.3 Narrative two

Within the second interview, I began to see a pattern emerge with her self-identification and having epilepsy. Frequently denying that epilepsy affects her swimming, she sometimes does not even believe that anything was ‘wrong’ with her. This seemed to continue the denial theme that was shown previously in interview one. As seen in the last interview, she seemed to use her epilepsy when discussing her swimming. This would not be to officials, but to others. Using her epilepsy almost seemed to be something to boost her ego. Very confident in her swimming ability, she contradicts herself when she first says she would have done more had it not been for her epilepsy. Later in the conversation, she says she has done so much because she did not want her epilepsy to stop her! Contradictory statements were common within an interview for Maya. I was sitting there confused, and again had to re-ask or confirm what she said, yet she would not remember or confirm the contradiction. This again, made analysing very difficult and I had hoped to present such contradictions within this narrative to make Maya’s personality more real for the reader.

Maya did state a minor connection with her seizures and exercise. Stating that she recognised more swimming concluded to more seizures, yet she did not feel they were harmful. She realised that maybe this attitude was not smart, but it did not seem to me that she would stop because of her seizures. Although I was fearful for her, it was also interesting to see her so relaxed about seizures. Yes, it might have been said, too relaxed, yet she was so confident in her athletic ability and concentrated on her end goal, that something like epilepsy would not stop her. The lack of safety precautions worried me as a researcher, and as a fellow SWE. I was struggling with knowing that these

actions could put her in danger, yet also did not want to betray her trust, unless I felt it was absolutely necessary. Discussing with my supervisor, I decided to wait and try to get her to talk more about what precautions she could do and make me feel that she is aware of safety measures. As she stated her neurologist knew of her swimming situation and intentions, it was discussed that I would not break confidentiality as of yet, and keep monitoring and questioning her actions within interviews.

Maya continued to show a strong athletic identity. She was very passionate about her swimming and that came across in her body language as well as her words. Hidden disorder maintained its lack of strength as a storyline for Maya. If asked, she would tell you she had epilepsy, as long as it would not hinder her swimming. However, examining such statements drew me to believe that maybe, when it was of personal benefit, hidden disorder was a theme for her as well. She does not want to be hindered by her epilepsy, and the result is to maintain a stance of denial of her physical limitations.

At the end of the interview, Maya seemed to stay within the steady narrative as seen previously. Continuing her sporting life, her only changes in structure would be if she could not swim because of seizures. A minor blip, it didn't seem to change her mindset and instead of listening to her body more, she made up for lost days. This could easily turn into a circular natured pattern, however, I never sensed too much frustration with Maya. It always seemed that she was a determined individual who would not be told she could not swim because of her epilepsy. I was interested if this would ever change or if her stubborn and strong mind would keep ploughing ahead as before.

8.4 Narrative three

Beginning again with the contradictions, Maya stated that she had two seizures in the water, then later stated that she has only had one, I did not know if this was just a forgetful memory or another denial statement. Upon re-questioning, it seemed that it was only one. It is hard to say if that was true or not. I wondered if she just had difficulty remembering a previous statement, as she had already told me of her troubles with her memory. Having to not dwell on such things, this interview seemed to present more contradictions to the connection of her seizures to her swimming.

Maya's statements linking swimming to benefiting her seizure frequency seemed strange to me because she previously stated that the more she swam, the more her seizures occurred. Stating this back to her, she seemed to not really care about the contradictions and just laughed. She did state that upon examining her swimming and seizure diary, she saw that when she increased her swimming, her seizures lessened. I saw the connection as well, but wondered what had happened earlier to cause the discrepancy. Also, she stated that she did realise that when she was tired, she could not swim. This showed signs of listening to her body, and since she previously would lower her swimming because of seizures, seemed to conclude that. In trying to make sense of her statements, it appeared that maybe her connection of less swimming and more seizures might just be a bad week, or the fact that she has to do less swimming because she's previously had more seizures! And then as a result, when she has fewer seizures, she can swim more. However, she seemed set in her mind.

Seeing the effect epilepsy has upon her swimming, it seemed to be the outside variables that annoyed Maya more. Continuing to discuss her upset that she could not drive, she relied on others and only swam in certain places because of her lack of ability to get to remote locations by herself. This seemed to frustrate her and I could sense that that was one major hindrance of her epilepsy on her swimming.

Looking at the hidden disorder aspect of her epilepsy, her lack of disclosure to officials in all her races had affected her ability to apply for benefits that she would need to live. She did not want to report that she required disability benefits, yet she had no issues with her health in regards to swimming. This was another source of frustration for her as the increased income would help her as she was a part-time worker and student.

Coming away from Maya's third interview, I felt that her constant contradictions enabled the steady narrative structure. She did not have many emotional high days, and her low days would be caused by the inability to swim as much as she desired. However, this did not seem to change her emotional response. She accepted this and either made up for it on other days or had come to terms with the fact that some days she was just too tired. Unlike other SWE having constant ups and downs or cycles, it seemed that Maya's constant plateau was affected by her mental state and denial of epilepsy, thus having less of an impact on her exercise routine.

8.5 Narrative four

In the last narrative, Maya continued very much down the same route as in the previous three. Maya seemed to be very consistent throughout the year, and being able to **portray** consistency was of great importance in Maya as a participant of this research.

During this narrative, Maya continued her contradictory statements and bringing her attention to these still did not clarify her statements. Believing that her seizures were not directly linked to increased swimming, her description of differing triggers seemed to also show a defiant stance that it is not linked to her swimming schedule. What would happen if they were? How would she react? These questions were asked of her, but she just said it would not happen, or that it would not matter because she cannot be told not to swim. Her reactions were always that she knew best about her body, and no one could tell her otherwise.

Throughout this interview, many statements had me in disbelief and I always felt like trying to get her to realise what she said! It caused great frustration listening to her contradict herself over and over again or ignoring the link between her seizures and exercise. However, it seemed that this was how she was able to maintain her exercise routine.

In this narrative, she revealed more about her social support system and how her mother now seemed to worry about her safety. Compared to previous interviews where Maya stated her mum's denial of her epilepsy, Maya's mother seems to have recognised that there may be a possible danger with Maya continuing to swim in certain health states. Having her mother recognise her health status seemed to be like justification for Maya. Maya seemed to enjoy the fact that her mother was worried for her, but also laughed it off, and thought it was just someone else over reacting.

Within this last narrative, I felt a continuum of Maya's denial and inability to change or adjust her swimming habits. Although she has stated previously that she

adjusts her schedule if she's tired, or sometimes does not swim, this does not seem to be something that she thinks was for the best. It is more of an annoyance for Maya.

8.6 Concluding thoughts

Maya's story was difficult to represent. I wanted to make sure that these four months of saying one thing, and then another, and then another was depicted correctly. Although Maya talked the longest in time out of all the participants, I felt there was a small amount of substance pertaining to the study in relation to the amount of interview time. This was frustrating, however, I tried to portray her persona within the narratives through their shape as well as constant contradictions. She was a kind, funny, and outgoing individual, and I was very excited to be able to interview someone so eager to accomplish a great event as swimming the English Channel. Although she seemed to be mentally tough, she was also very stubborn. This caused her to fail to acknowledge safety concerns and how her seizures could have an effect on her swimming or vice versa. Although she stated that she did not think they were linked, I felt like she was saying that because if she did, what would be the outcome? Does she just stop what she loves so much? No, this was not in the cards and her mental strength has kept these thoughts at bay.

I do think that there was a connection between exercise and epilepsy for Maya; however, I do not think that this will affect Maya's swimming. It seemed that on most days, she did listen to her body, and I was pleased with that. It would be interesting to witness more of Maya's story and see if anything changes up to her event and beyond.

After talking to Maya for a year, I have every faith that she will do her channel swim and succeed. She was strong-minded and had a passion for swimming, making me feel that she would not let anything stop her. It was interesting to note, that upon reading her narratives for clarity, she reported back the recognition of her denials and contradictory statements. I do not know if this will change her future exercise habits, but for the time being, I am excited to see what she will do in the future.

9.0 Rose's narrative

9.1 First narrative

I don't know. They're... we don't really talk about it really. It's weird cause, umm, I don't know. I just felt at the time that I wasn't really getting enough support from my family. It was a really, really difficult time when I first got diagnosed...

Yeah, but I was on Topiramate¹⁸ at first, for a while, but that just really didn't agree with me. I just was terrible on it, like really tired and I couldn't think straight or anything... But I just... it was, just didn't agree with me at all. I had a really bad time on it.... I was just tired. I couldn't really do anything, like, even go out with friends and stuff. I've always done a lot of exercise. But couldn't do any exercise, I wasn't working... I don't think it was the medication itself that was making me depressed, it (medication) was making me feel so helpless and that in turn was making me feel depressed... The exercise thing sort of took a backseat... And as soon as I started taking Lamictal,¹⁹ I could see such a huge difference, it was like I was back to my old self.

In this past year when I have been feeling rubbish, I think exercise has been one of the things that, you know not THE one, but one of the things that sort of helped me. Gives you some time to sort of get out of your head a bit, I think, don't you? Concentrating more on what you're doing. There's like the physiological thing, isn't there? Releasing all the good hormones and things, making you feel better... I sort of see it as an outlet for feeling better. 'Cause, like, work's rubbish and I get to go after work. It's a bit of release. I think I've sort of always seen it as a bit of a get out really

¹⁸ AED

¹⁹ AED

from my other things... I'd come out of work and my heads just, so full of stuff and rubbish things I have to do. Umm, but you know, I go swimming with this friend, we go straight after. It's just nice, I'm sure it's a mix of just chatting with my friend as well and the actual exercise, but I feel I don't got that in my head anymore. I feel a bit freer. And, it will make me, like at the time, I will feel better, feel bit more awake. Like if I'm really tired, it sort of fills you with energy, doesn't it? But then later on I will feel tired again. But not too tired, just an, uh, glad that I've done it cause it has made me feel tired now so it'll probably make me sleep better. It makes me feel better as well because it's not, I think if you don't, if I didn't do anything like that, some nights I'd just go to work and come home, have dinner, go to bed, go to work... It would feel like all you do is work then, so it's nice to have that something extra because it's like a social outlet or it does make you feel a better or it does make you forget about the day... So, generally a lot, lot better. I've started to push myself too much in the gym and I will feel, like really tired afterwards, but then feel a bit better later. But then mostly exercise makes me feel better straight away, bit more energised... and I never actually felt twitchy in my head during exercise. Well, I suppose actually the other day in the gym I did because I was really tired and felt like I was probably pushing myself too hard, so I stopped. Other than that, especially when I am outside, or running outside, I'd never feel that twitchy when I've been exercising... I'm obviously more, more awake and more energised, but if I have done a lot of exercise, then maybe later on in that day I might feel a bit more twitchy.

Running, cycling, Zumba, and swimming... I do a fair about of running. A bit of cycling. Running would be the main one I'd say. So I'd either go out on the road or I'd

go to the gym. If I go to the gym I'd go to, on the treadmill or the bike. I do a Zumba class... and swimming, I swim a couple of times a week... Well, I always go swimming twice a week, always. Zumba once a week always. And then the others probably a bit more up and down. At the moment I probably go to the gym once a week. Umm, cycling I haven't been doing because it's been winter. Well I'm supposed to be doing, well I am cycling from Coast to Coast in April so I definitely will have to get back on my bike... So then when we don't cycle as much, we run more.

Running I probably do better if someone's with me. I think because, just, you're not as conscious. I'll have my music on and be like, "Oh, I'm getting tired. Just to the end of this song, just to the end of this song." Whereas I think, if I'm with someone I'm chatting on and you don't realise how much you've done. For that, I'd rather prefer going with someone because I think I do better. Cycling, yeah, but that's because I don't think I'm very good at it. So it's more of a confidence thing. Gym I prefer to be on my own. Zumba I wouldn't go on my own. Swimming either way, I'm not really bothered. With the swimming, I really do just once or twice a week with a friend from work and it's really more, we go, we do go for an hour. But it's more like we'll be swimming, going up and down chatting, it's not like vigorous swimming. But if I do go with my sister, we're quite good at, we'll go for it. And walking yeah, I'd probably wouldn't go on my own... Oh actually I have been, but as a rule it's very likely that I'd go, "Oh, I'm going for a walk." If I'm going to do something, I'd go for a run. I think the only time I'd go for a walk was if I wasn't able to run for any reason. If I'd been like injured, or like not well because that's a bit more, I see it as a bit more sociable thing to do, that's cheap. Go for a walk. Walk to the pub.

So, if I'm tired... I'm conscious of pushing myself a bit too much because I don't want, I mean they never sort of said exercise would add to that. But to me, it's just making your body more tired, isn't it? It's just putting more pressure on your body. Umm, see I, it's probably made me not do all, or not do as much at the gym. 'Cause, I can sort of feel, when I get a bit tired I can feel a bit twitchy, and I don't know if it's just psychological... and that's the best way I can explain it really, a bit twitchy. Physically, I wouldn't be twitching, but in my brain I feel a bit twitchy. But I have had a couple like my foot would go, but my neurologist said that was just, a form of mini-seizure or whatever. But that hasn't happened since I've been on medication, so that's obviously controlling that...

So I suppose, if I was really tired and I really wanted to do something, I'd probably would rather go for a walk than a run because I am very conscious of pushing myself. I think I am conscious of making sure that I've eaten enough to exercise and drunk enough. Whereas in the past, I would be pretty blasé about it. Whereas I'm pretty conscious about pushing my body, not pushing my body too much... Umm, but then I do now, I do things to push myself, like doing the Coast to Coast. I wanted to push myself to do it.

I was told by my GP, just when I was feeling so down on that medication, that exercise, should, would... help. But the neurologist, no, nothing. I never really sort of thought, until the medication, I never thought it would or should affect it... My dad likes me to exercise. I don't know if he just doesn't connect the exercise with the tired, I think he connects more tiredness with not sleeping... No, I don't remember anyone ever saying anything to me.

I think, I dunno. I'm definitely more conscious of triggering a seizure during exercise... I think it completely went out of my head when I finished Uni probably cause that was like a big check, finished one step from the other. I can't even remember being... 'Cause I've been in my job one year now, one year since I've been diagnosed, and one year not been diagnosed, and I can't ever really remember it being in my head that year, that first year. It maybe was more than I realise now, but I think, I would have, I wouldn't have said to you then that it would have stopped me going to the gym. I would have just kept going, but it's like, definitely a conscious thing now...

It's strange talking to you actually, really, when I'm speaking how much I do think about it. 'Cause I think, recently I've felt better and don't think about it as much, but I probably do. I probably think about it all the time...

9.2 Three months later- Second narrative

Well I've been doing a lot! I cycled from Coast to Coast in... April. So that was really good fun. So up to that I was sorta doing a lot cause I was training for that, three months.... So that was when I really started training, sort of going out most weekends on my bike. Umm, and, yeah, I do bits in between like I normally do really, swimming, running, but mostly biking cause I was training for this ride. Umm, which was really good fun actually. I was a bit worried about it because it was sort of, it was a bit, it was sort of a long ride. It's 150 miles and we did it over 4 days. I was really looking forward to it, but I was a bit worried, "Oh, am I going to wear myself out?" You know? ... I didn't even think about that as a consideration at the time when I said I'd do it, which was last summer! It's one of those things where you say you'll do something, "Oh yeah

that sounds like fun,” and then it comes closer to it and you think, “Oh, I actually have to do it!”... I was worried that it was going to be bad for me, in terms of my epilepsy, but I think it was good.

So as it sorta got closer I was a bit worried I'd do a long ride, and I'd get in at the end of the day and I'd be really, really tired and I thought, “Oh, if I had to do this and get up and do it again for three days.” But, when I was away, I wasn't aware of it at all. I think it's a different kind of tiredness. Like a physic-, like when you've been out on a bike all day, it's like physical tiredness, and then you sleep, don't you? I think, the tiredness that comes from not sleeping and being stressed and stuff, I think that's what triggers my... even if it's not a proper fit, but when I get sort of twitchy and things like that.

I think it was probably the fact that I was exercising! I think sometimes I get myself in a bad, I get worried. I get myself in a bad... thing, “Oh I feel tired, what if I can't sleep tonight?!” And then I get more tired! 'Cause you're just, you're out and about all day and that's what you're thinking about... And it was just, sort of, you know, focus on the ride, and then get up and do it again the next day. And because you're so tired (laughs) you don't really have any other time to worry about being tired. I think that is the big thing with me really. I get in my head that I'm going to be too tired and then it's that cycle when I get in bed. “Oh I'm tired and I'm going to be more tired, I can't sleep.” But umm, I don't know, that was really good. I quite enjoyed that. I think that was really good for me actually. Umm, since then I've been a bit... rubbish (laughs). Since I got back, it was about 4 weeks ago, I've done a couple bits, but I've had about a week or two off just because...

But I have been doing a bit recently, 'cause I'm doing a run as well in a few months so I've started to train for that. So I've been running, a bit more now than biking. Bike's gone away (laughs). I've not seen it since... Yeah, I... I don't really try, I don't really worry about that as much as sort of making me tired, cause I sort of see umm, cause I come in from work and I go for a run and it always makes me feel better.

In running I can manage, you can't really fall while you are running. So yeah, I'm quite looking forward to, sort of, training. Run on my own for about 5 miles the past few times, so that's a start... Yeah, no I'm not worried about it, I'm fine. I'm actually less worried about that than I was about the biking just because I've never been that long before on a bike. So, a lot of scope for accidents, but I didn't have any accidents, it was ok!

Uh, I've gone twice so far this week and I might go again when I go back. That's average, about three times, two to three times. Like, you know, I've done three times last few weeks 'cause I've been training for this thing, whereas before I was biking, so it might have been once or twice.

Even if I come in and I'm really tired, going for a run, sorta suppose it's the hormones or the endorphins, whatever it is, I come in and I feel less tired, I feel all ... relaxed or happy. I don't, it doesn't really stop me from going really. If I'm feeling really tired I don't think, "Oh, maybe I shouldn't go?" Because it always makes me feel better from it.

I personally don't really associate seizures with exercise. I do to a point, but I don't... I just don't connect it to sort of physical tiredness. I'm sure it's got a link, you

know, if I haven't slept enough, but not sort of the physical tiredness you get from exercising... I wouldn't relate it to tiredness from exercise. That seems to be the sort of thing that really helps me... rather than mental tiredness which is just... you know, you are tired and can't sleep... I think, when I get in, when I've done exercise I feel physically tired, in that my body's tired, I seem to feel so relaxed. And so, I just relax and sleep better than when it's a tiredness from being stressed at work... I feel it (exercise) kind of stops me, it's the relaxing thing, exercise really helps me relax.

It's like a bit of a line I think about, "Oh I'm not going out today because I'm too tired." But on another day I might feel tired, but I'd go out because I don't think I'd be too tired and it would be a risk. But I'd think that at the end, it would be better for me because I'd be tired and I'd be asleep... Yeah I don't know, if I generally felt a risk that I'd have a seizure and felt a bit seizurey, I wouldn't go. Whereas if I didn't feel seizurey, I would go. So I suppose that's the basic, you know, it's not that every time I'm tired I feel seizurey, I can tell the difference. There are days where I'm tired because I haven't slept very well that night, but I don't feel as if I can go run, I feel a bit twitchy. And I can sort of feel in my head that I feel a bit funny, and I think that's what the difference would be. I might just be tired from the day's work, then I would go. But if I was feeling, really twitchy or seizurey, then I wouldn't. I would feel like I was already increasing that risk.

Yeah. Well, in the ... well, I think in a way it's about finding a balance between being aware of it and thinking about it. Be responsible, but not let it take over your life... But I suppose everyone, you can't really compare because everyone experiences things.

But I think you do have to take a step back and think, on the grand scale of things it's not that bad.

It does get, sort of easier I suppose. I am weary, as well, that I need to keep it into consideration. I just can't let it go out of my head because then that's what happened last time, the first time I had a fit. For the first year I was so aware of it, and seeing the doctors, dah, dah, dah. And then it all died down because I didn't have another one, and so it sort of went out of my head. And since I wasn't on medication at that point, I forgot about it really, that they sort of said, "Oh you might have another one, you might not," blah, blah, blah. So it went completely out of my head that I wasn't sorta really taking care of myself like I should have done really... You never notice, you don't know the trigger till it happens, do you? That's the thing. And even then, you have to go too far to know where too far is, don't ya?

Probably like, I'd say, I don't think I'm ever not aware of my epilepsy. I'd like to say I think so, 'cause like, taking the tablets every day. You can't not be conscious of it, can you? Because every time you do it's like, "Oh" again... Yeah, it's always there, it's always in the back of my mind. I wouldn't say, I think it's difficult to say I'm less conscious, but really less anxious now. The longer it goes on without me having a seizure and I am either taking my medication and I'm driving and I am trying to be a bit more responsible and sleep a bit more. People are starting to get it's just a part of... me, and it's honestly quite sort of, "Well done for controlling it," sort of thing. You know? It's kinda like, it's kind of like one of those things at the end of the day, the only person you have to look after is yourself. Bit like, being conscious of it, for myself.

It doesn't stop me from doing anything anymore. And you know, anything that I stop myself from doing in terms of staying out too late and drinking. I don't see as, I don't see it as doing it for the epilepsy. I see it as doing it for me. It's not even such an effect on my life that I can't go out and I can't drink, it's just curbing it a bit. And I'm fine doing that for me.

However, I'm beginning to be a bit blasé about it, but it's still there. The driving was such a big thing for me, and since that's come round, I just feel confident. I know you can't say how you're going to feel or what's going to happen, but if I had another fit, I feel I probably would go back to how I was last year and a lot worse about it and a lot down. It is just a big thing for me. I am sure I can change my lifestyle to the point where it couldn't be, where I could move to somewhere which isn't in the middle of nowhere. I could find a job that didn't need to drive would help minimize that effect. Umm, but this time I was really thinking of it as just this year and getting through this year. But, um, if it did happen again I think I would have to think again because I don't think I could continue with my life where I could just think, "Oh, I'll just sit in this year, see if it happens again." But, I'll just take it as it comes. Umm, I do think I still think about it a lot, but sort of been able to come to terms with it a lot more because it is having such a less impact, if that's a way of saying it, a less impact on my life now.

People sort of, it's very... people sort of think that with epilepsy, they sort of see the flashing lights thing and they might say to me, "Oh, can you not go to a disco then?" And then I sort of say, "It's this that triggers it, so..." But no one's ever said anything to me about it in relation to the exercise. My friend who went with me on the bike ride knows, well a couple others actually know. And neither of them mentioned it, other than

saying, “Oh, have you got your medication?” Yeah, they did sort of ask if anything would sort of, sort of trigger it. You have to fill in a medical form and carry around it with you and I put all my information of my medication on there and the people I was with knew in case anything did happen. But, just never talked about it really.

No, I don’t know what it is. It’s not a big deal, is it? If I was just a bit more matter of fact with it than, they probably would be too... I suppose it’s just, it’s like... maybe I don’t want... it’s something you don’t want to have, so you don’t want to tell them... I don’t know... I get defensive. I don’t know, I don’t know why. (long pause) I don’t know, I don’t know if I would even say it was nerves. I don’t think I’m nervous about it... I don’t know, I don’t know what I think. I don’t know what they would think, I just... You know, I wouldn’t want to tell somebody. I’d only tell somebody if I have to... So I just sort of, depends who it was, but sometimes I just tended to be a bit vague. Say like, “Oh, I’ve not been well.” But I don’t know what it is, I really don’t. I’m not particularly worried about what anyone will think, because I do think it is one of those things that people will think, “Oh, ok.” Like more people actually do than you realise I think sometimes. Like as soon as I said to people, “Oh, I have epilepsy,” “Oh my, you know so-and-so has it as well.” (little laugh) And it’s actually a lot of people that have it in some form or another, or who have had it.

9.3 Four months later-Third narrative

I had a fit not long ago, ’bout the start of August. So yeah, bit unwell after that... So I was a bit, like I said, knocked out for like the whole week.

I had it while exercising. I was actually quite surprised I had it in the evening as well, 'cause I've only ever had them in the morning and that's because I sort of related them to being tired... I know I've only had two before, but if I've sort of sensed, a pattern to it. This was just completely out of that pattern, so it was just a bit... a shock really... We went out for a run, in the evening with a friend. Was fine, doing fine. I hadn't eaten, which is, everyone's had a go at me since. Umm, because I don't like to eat right before I run! I was going to eat when I got back, I just hadn't eaten yet. And all of a sudden, like I said, it came on all of a sudden. I was just running and talking and then it came on all of a sudden, like I was going to be sick, really sick! But I had been running, and hadn't had anything to eat. And you get that sick feeling, don't you, when you're hungry. So I said to her, "Carry on, I'm just going to have a minute." And sort of got like down on the floor a bit, and that was it! That's all I remember, like, I kind of remember really wanting to lie down, and my friend being like, "Come on Rose, Rose." And then, I kinda remember lying down and her talking to me, but not being able to do anything about it. But I was aware of her and her saying my name, but I just couldn't do anything about it. It was almost just like... (pause) I think I had my eyes open 'cause I remember seeing her, but I couldn't, I couldn't, like I wasn't there. I couldn't do anything about it. I don't think I was fitting at that point... Good thing actually that I was with a friend, 'cause if I was on my own, I don't know what I would have done.

I didn't really think of exercise, as a link. I actually did think it would be interesting for you. For your study (laughing). I did it for you! ... I was tired. I'd been and had a nap. If I hadn't slept very well, a couple of times I have a nap when I come home from work, like not very long, just like, when you're lying down watching TV and

you fall asleep. I'm always less worried when I had a nap. But I just think, well maybe my brain hadn't caught up and it was just too much stress, and I hadn't eaten. I hadn't taken my medication, but not in the way that I've missed a dose. Just in the way like I take it when I get up in the morning and before I go to bed. So I just hadn't taken the evening dose yet. But, I think like one dose... it stays in your system, so...

'Cause it (medication) seemed to be working fine. I was quite surprised to be having one, to be honest. Think I was kind of, became dependent on it. I thought the medication would sort it, so I probably was pushing myself a bit. Because I now know the medication, obviously it's never going to be, it's never going to control it completely. But it seemed to be controlling it.

Yeah. It's a difficult thing, because it's something you enjoy and you don't, it does affect a lot of things. It's like one of those, you're fit, and you go and you exercise, and I don't know about you, but it's de-stressing isn't it? Like, running around where I live is really, pretty. So when it affects something like that, what you enjoy.... it's a pain, isn't it? It's not nice. 'Cause you're wanting to go out and you always have that in the back of your head. You know, you probably more than me, but me more since this! 'Cause I've never really... I don't know... But I never saw it as a connection for me, you know? There's so many causes, and making lists and you say it could be this, this, and this. And I've always said it's tiredness with me. In the morning, when I've not slept very much, I always thought it was that. I think because I just slept, that was always my thing that I was safe, that I've slept. That's why I probably went out and pushed myself, even though I hadn't eaten, even though I was tired, because I thought, "Oh I've slept,

I'll be ok." So that's been the thing, I think, that I'm most conscious of. It's another thing really that I have to think...

I'd say it's a bit on my mind, just to the fact that the first time I went out I was a bit like, "Ooh" about it. Not to the point that I didn't want to go. And I was talking to my friend about it the other week, and you can't stop doing stuff, can you? You can't let it affect you. I mean how many times have I gone out for a run and it's not happened?! It's just one unlucky time, I suppose. But, I think I definitely will be a lot more conscious of it... But it really worried me, in terms of like, going out running on my own, 'cause I always go out on my own. I've been out once, since I've come back, I've been out once and sort of saying to my sister, "I'm going to stick to main roads and I'm going to go here, and if I don't come back..." (little laugh) You know, 'cause, it is like, something I really like doing. The thing I like doing is going out for a run on my own. I like going with other people as well. But I, sometimes I get home from work and I think, "Oh, I want to go out for a run." I think I'll be fine, I think it's just getting back into it and being more sensible about when I go. And eating, and if I'm tired, just miss it out sort of thing... But it did, worry me a bit, you know; put me off properly going on my own as much. 'Cause obviously I don't know if it's exercise related, but it's umm, I think it's just a combination of everything, isn't it? Too much on my body, whether it's tiredness or stress. Which I think it was just a bit of all of them... So I'm sorta still getting back into the old routine. So I haven't been really exercising that much. (laughs)... Just in case, like I said, just letting someone know where I am. Like, I wouldn't have bothered before, would just be like, "I'm going out for a run." Whereas I'll tell my sister or my mum or dad where I'm going, how far I'm going, so that they

can know when to expect me back sort of thing. And just stick to the road, stick to the main road rather than going off track.

I'm less likely to go out exercising on my own. I have been out on my own, but I prefer to go out with somebody now. Whereas I would happily go out on my own before... My sister's not a runner, but I would always ask and she's like, "No, why would I want to do that?" But now she's been coming out with me a couple of times. Maybe she prefers, I mean she hasn't said, but maybe she prefers someone to be with me. That's quite nice. I suppose I'm getting her fit. And she wants to do this bike ride with me, so we're going to be going out biking. Probably not on it properly in winter, 'cause it won't be that safe. But you know maybe when it starts getting nicer, maybe next year we'll be going probably out on the bikes more than running.

And I can't remember if I told you I did that bike ride from Coast to Coast? And the people I did that with, she's just arranging another one, bit longer this time. So, that's in June, so I would be training for that again. 170 miles I think, I don't know how many days we'll do it in. We did our last one in four days and that was 150, so maybe about the same... I really, really enjoyed it, it's physically difficult, but it's nice socially. It's nice... I am looking forward to it. I can't say I even thought about my epilepsy the first time.

When my friend said about this bike ride, I was just so like, "Yeah, I really enjoyed the last one, it'll be great." But now I'm like, "What if?" It's a lot of on your body. But I was FINE last time. It's just... it's just one little thing, isn't it, that affects you so many times! I'm just like, I've done Coast to Coast, I've done runs, I've been out

on runs, like hundreds of runs. And it's just that one time when it was too much, but it's starting affecting. Like I'm thinking what to do next year, I want to do this bike ride, am I going to be able to do it? What happens if I have a seizure when I'm on the bike ride? And all that kind of a thing. So... yeah, I think it probably will affect me more than I realise.

I was exercising quite a lot. It was just running, really. I was in a fairly good routine with swimming, but I only ever do that during school term-time, 'cause it's at a school I go for swimming... And like I said, I tend to go through a period where I go three or four times a week, and then don't go at all. (little laugh) To be fair, the past couple of weeks I've been going once a week, and that's been alright... So we were getting up to quite long runs. Probably an hour? But this one, I don't think this one we were going on wasn't going to be that long. (laughing) I know, I'm laughing about it, but sometimes you have to laugh, don't you? (laughs)...

If anything, having this fit has made me a bit more sensible. Like what people have been saying for a while, I kind of just brush it off a bit. Like looking after myself, not pushing myself too hard... I think... like I said, people were saying you have to look out for yourself... And you don't realise it's too much, until it's too late, do you?

Just general, just doing things for me, whereas I like doing things for other people. Being like, "Oh, I can't let them down" and "I can't not go." But people do that to you. And I wouldn't be bothered or offended, you know. So I think it's just being a bit more like that. Just being a bit more.... looking after number one. (little laugh) Be more confident in myself to say "No," or do what I want to do. Things like that, but this

has obviously been a big factor in doing things like that, and choices I've made. Staying out, or not going out. Just generally look after myself more... Like, I do work hard and I do deserve a break...

Yeah, definitely, like when I went that evening with Jane²⁰, like if that was to come round again, I wouldn't go. Yeah, definitely. I used to go just willy nilly 'cause Jane is very busy, we just go at random times. "Oh, do you wanna go at 8? Do you wanna go at 3?" Whereas now I try to get back into a routine and come home from work and go straight. I come home from work straight at 5, so at the moment it's not dark, so that's a bit better routine. And I make sure that I've had my lunch, and probably have a snack on the way home, just have more of a routine about it. Like, if I'm tired, I tend to either come home and go for a run, or go take a nap. I wouldn't now do both. I wouldn't wake up from a nap and then go because I don't think that's good for me. I think that's partly had something to do with it last time. I hadn't come out of that sort of sleep state. I was still too much in my body. If I'm that tired where I have to come home and take a nap, then I'm obviously not in that good physical state where I should go out for a run. I just used to push myself, it's just silly really. I didn't need to go out for a run at 8 o'clock in the evening. It's just... now I'll be like, "I'll go tomorrow when I feel a lot better."

My friend, Jane, who I run with and had the fit with, she's into alternative hypnotherapy and all that sort of thing. I've never really thought about it. Because I think very much, it's a medical problem, and medicine has to fix it sort of thing. I'm lucky that I'm in the situation where I can pay for something like that, so it's just worth

²⁰ Pseudonym

it giving a go. I think, even more so, just generally feel a lot better within myself, it's made be more open to people about it. I think the last time I spoke to you I felt that people weren't very supportive. It was really interesting talking to Jane about it 'cause I never saw it, like, from a friend's point of view. She sort of said, "You're always so closed off about it, so I shouldn't bring it up, but you kind of go really, introverted about it." I never really thought about that before. But, you know, people, I think will be as supportive as you let them be. If that is the way I react, then people aren't going to push it, they probably will assume I don't want to talk about it. So, I think I've been a bit more... open. Sort of bringing it up with other people, I suppose. Like, especially, my friend who I went away on holiday with, I talked to her quite a lot about it because we're together all the time, for 6 weeks! And I wanted her to know, what's going on in terms of me being worried, and if I didn't feel very well. She was quite good at saying, "Go to bed. Don't go out for another week, go to bed." "Oh, ok." (little laugh)... Yeah, so I think I've been a bit more open about it.

Well, it (epilepsy) used to be like, really, about it, it used to kind of make me... I felt quite negative about it I suppose. But you know, like when people talk openly about it, I'm like, "Yeah, that's me as well." But it's... I think I just see it as part of me now; I think I used to see it as a thing. I didn't like it and I didn't like hearing the word... The first few times you have to do forms, I didn't like writing it down. But now I'm like, tick the box. (little laugh) That's just me. That's me, it's just a rubbish part of me and I probably just got used to clearing it off, not thinking about it. I found it really helpful that I've done this with you, I find it, because you know a lot more, and experienced and it's just nice to talk to someone. Because like I said, I have a lot of good friends, but it's

nice to talk to somebody who knows, who actually has it... It's a bit of support, isn't it? I mean, I hope I'm helping you, I feel like you're helping me too...

So many people choose not to exercise and I'm almost like, "Well you can! You can do it fine. You should go, you don't appreciate it. You don't know what you got till it's gone," kind of thing... Yeah, like I said it's a bit of a shame that it's something you enjoy, like a hobby that's good for you, something separate from work, and it kind of gets affected. It's so frustrating! I just want to do something that isn't affected! (little laugh) Which is, sort of, seems to be getting less and less.

9.4 Three months later- Final narrative

I've been coping with it (epilepsy) a bit better. I don't know if it's because I've gone through it before or generally things are more in place, like I don't have to deal with the medication, getting used to the medication. Feeling a bit better about it because before I've never had to deal with it and didn't really know what to do... There hasn't been many peaks and troughs, it's just been kind of a constant thing. But there's nothing I really need to get out now. It's what it is now. This is just what it's going to be.

I think before, I kind of had seen exercise as something that might even be beneficial. I think that's the key. Before I saw it as beneficial, whereas now I'm weighing the benefits against the possible consequences. I never really, I don't know, obviously I had a consideration that it (exercise) might make me feel tired and then cause a fit, but I never thought it would happen while I was exercising. I don't know if it's just my, like, what I thought caused my fit, just didn't... I'm always out and about and doing... And being out and about in general, you feel very awake, don't you? I

didn't connect the two. Thought my fits were when I was very tired and... not relaxed, and not pumped up from exercising.

Yeah. Well, well, the only time it's ever resulted in a seizure is that time in August. But I'd probably would be more quicker to stop now. If you are really pushing yourself when you exercise, you do feel sick, don't you? Whereas if I felt that before I'd be more likely to push through, whereas now I'd be more likely to stop. Have a minute out. Have a drink... I went on a bike ride yesterday morning and struggled a bit actually, cause I'd been out Friday night and I'm too good to say, "Oh god, if I?" 'Cause it does start, especially since having my last fit on a run, that side of it occurs to me a lot more than it used to. So like when I was cycling up a long, long hill, when it's like that (shows slant with her arm), and you can't get anywhere but go up a massive hill (laughs). And you know when you start pushing yourself and you start to feel a bit sick... Every time since, I felt sick first or afterwards and I've started connecting them a bit now. And you start to think, "Oh god, I feel a bit sick." And you know, you start to worry a bit about it. I'd be like, "Should I go on? Should I go back? It's not worth it."... I think I realised yesterday more so than running, with the biking really. I don't know, well it might be a bit silly, but I associate biking with being more dangerous. When you're biking out on a road, and you have a seizure, it will be a lot worse. I think I don't realise how much to the extent that I do think about it, but I just completely didn't link them before cause I'd only ever had the seizures in the morning when I'm tired... But when I am on a run in the evening... Now it is a bit of a concern for me. I think it makes me a bit more, not being a bit more complacent about it. Like, "Oh, it's past 10 o'clock, I'm not going to have one."... being a bit more aware.

I mean the longer you go without having a fit you become a bit more... confident in that you can exercise... But I think straight after the fit you're kind of like, unsettled, worried. But give it time and you feel a bit settled more. Maybe get less anxious about it. A bit more, sort of, "Why don't ya, get active again?"

I've only recently just started to get back into the exercise thing really. I've always done yoga and Pilates, which is just something, not much, just relaxing. But never ever worried about having a fit when I'm doing that, which is interesting. It's not physically demanding, is it?

Umm... I don't know, I guess I haven't really figured out what my point of, when I should say, "enough is enough." I always tend to be about pushing myself. I always have been... I'm not really good at saying, "Oh maybe I shouldn't go, maybe I'm a bit tired. I haven't really had anything to eat." I just kind of get it into my mind and then go for a run and that's it... It's just when I go out and start to feel ill, that's when it occurs to me. I've been out a lot longer on my own, which I wouldn't have normally done before, 'cause that quite worried me, since having that last fit... So because of that, I'd like to think I'd be a lot more sensible about going out. Maybe think a lot more about it. Sorta tell and be quite specific and tell my mum where I'm going. "Oh I'm going to... If I'm not back in..." Umm, just generally a lot more anxious... I also probably don't enjoy it as much 'cause I'm getting anxious.

No, because I think partly for the reason I wasn't going out on my own is because of the fit (whispers fit). I think, I was a bit worried about it and I didn't have anything which to work towards. I think it is difficult, going out on a bike, it is difficult,

cause I hadn't been out for ages, and you do have to build up again, and it's horrible out there. You think, "Oh, I can't do it!" It's almost like a cycle when I'm not going 'cause I didn't want anything to happen, so then I went less, less and less, and then I was really unfit, and then I probably was worse off. Umm, it's just like having the extra thing after Christmas, having something to work towards, wanting to not be unfit and wanting to be able to do it. That sort of made me get back into it. I think I needed that extra element to push me. Which made me feel, you know, that I wanted to go out on my own again. I don't know... It's difficult cause there's sometimes I'm like, "Well, I don't know." But you can't let it shape, it's a shame, 'cause I like running, and I would want to do that on my own. It almost feels like, if I stop it letting me do that, it's another thing, isn't it? That something that I enjoy, something for me, that not enough people probably do. But I don't want it stopping me doing it. I like going away by myself sometimes. It's a good stress release, isn't it? ... So it wasn't an immediate like, "Oh, I know I can go out on my own again now." It was kind of more like the time was... The time in between having the fit and going out again probably a lot to do with it... a bit more ready... Yeah.

I think this time, I think since it was to do with exercise, I think it was more a massive... I just never sort of thought about it until talking to you, a massive, massive consideration. I saw it as a nice thing for me, a get out. You do feel good about yourself, don't you? You get a sort of, you feel better, you get fitter, and all that stuff. Your body feels better... But now I'm a bit more like, kind of, waiting... you know, don't want to make myself ill again. I don't see it as perhaps a... I don't know. I think before I very much thought it of something very much for me. Something to do for myself, and now

it's more of a worry. I sort of think a bit more like that with the benefits and the downfalls a bit. Before it was very much like something to do, to even stop me thinking about it, come away from feeling ill and possibly, 'cause generally it's good to keep fit, so it would help towards not being ill. Now it's sort of the other way round. I'm a bit like, "Is it worth it going out? Will I make myself ill again?" I felt a lot freaked out about it in that way.

I think I have to think a lot more about it now. A lot of people are a lot better at doing mind over matter. I think, in the past I was a lot better. I'd be like, "You can do it, push through, push through." But now, to me, pushing through it, the consequences have jumped slightly. It's something a lot bigger... I'm probably less likely to push through it, which it might mean it might make me longer to build up my fitness again, I don't know. It's just not, you know, the consequences are just very large, in consideration. So I'm less likely to do it now... than I was before. But that is very much more of an element when I'm on my own, so I just put the two and two together and think about going with somebody else. And I think it can be just depends on the day... You might not have eaten the right amount, or it might be that time of day, but on other days you might just be so much better... I don't know how I'll be, on this bike ride. Maybe cause I did it last year... it was very much I had to push myself, but it was also very much, like, "Come on everyone else is doing it, keep up with the group"... But now I will, I think if I am struggling, even if others are struggling, I'll think I'm the only one that might have that (seizure issue) as a reason to quit. So, you know, I might find it difficult... find it difficult, but might still keep pushing. I can do it. I might be tired, but I can do it... You don't know, you don't know till you're there.

I've learned to be a bit more conscious of listening to my body in terms of how I feel, if I'm tired, and do I need to stop for a drink or stretch. Sometimes you stop... Like if I'm feeling really tired, I'd stop and walk for a bit, but just keep a bit of pace with it. But I'm a lot more likely to do that, to stop, to be more aware of how my body's feeling when I'm on my own... That's when it gets me. That's when I worry about it. I sort of compare, when work's as stressful and I'm as tired. You know? "Why is it not this time?"... It's a combination of little bits, isn't it? You think, "Is it coming up to this point, or will it come to this point?" I hate that sort of anxious feeling, of like, "Am I going to have a fit?" I struggle to get out of it. And I would, probably if I would have a fit, that would probably be a massive contributing thing. If I have all that anxiety, it doesn't help. But in the end what I think, it's always going to be there. Regardless of how long it's been, it's always going to be a possibility.

I do tend to perform better when I'm with somebody, maybe 'cause I'm not as, you know, in my head about it I suppose. You know, having a little chat, you're sorta of pace each other, don't ya? It's always taking your mind off it, and you think, you better keep going... Like, yesterday morning I wouldn't have gone, if it would have been just me. I wouldn't have gone on a bike ride, but I had arranged to go with a friend. But I didn't feel too well, and I hadn't taken my pills, but I had arranged to go and I didn't want to let her down and all that. But if I was on my own, I would have turned around or would have... not gone. (little laugh) If I was running, I would have been more likely to stop, give myself a minute for a drink, or whatever... Maybe that's probably one of my downfalls, maybe I should just push through it, it's mind over matter, but in my mind, it's a bit like, "Oh... I don't feel very well."

My friend I'm doing it (bike ride) with, been out on a run a couple of times together. Lovely little training run. Quite recently since the weather's been getting nicer, I've kind of been doing every other day, on a run... But that's what I tend to try to keep to, every other day... Yeah, I'm enjoying it really. I think that's a lot to do with feeling better, I think you forget how it does make you feel better. And I imagined it's probably helped with the sleeping thing as well.

My friend who was running with me when I had the fit, is going to be on the bike ride, and my sister's going to be on the bike ride, and they're really much, "Are you tired?" And especially my friend who was on the bike ride last year, she would be all like that since the... it would just be generally more of a consideration. Pretty much for me but just in general. But... my friend is really good, she wants me to do it with her, she's not like, she doesn't want to stop me. She's very much like, "How do you feel? How are you?" each night. "Are you tired?" She would consider it before we go. She just, it probably is not nice for her, it wasn't nice for her... she probably doesn't want to see that again, so...

I think I'd struggle if I was told to stop exercising. I probably would exercise anyway, to be honest... I don't know... But I do tend to do all or nothing with it, but I've already done a few months of the yoga and Pilates and the occasional swim. Um, so, you know I can't say like I do a massive lot all the time. But when it does get to the stage where I am doing it every night, you do realise how good it is for you and how much better it makes you feel. Which I think I've realised more this time than any other time, because I had the stress of work and not sleeping and things. And, you just realise how good it is for you and it's just like even the feeling of being able to do it, isn't it?

It's nice. Even when I wasn't doing as much, I knew I could. I knew I could. I could go for a swim if I wanted to. Umm, and I know if I'm ill or if I'm injured myself, I want to go more than ever! 'Cause you're just sat around. I think I would really struggle... So if someone turns around and said, "It's the exercise that triggers it, you can't exercise." I probably would have to take it on board because it's for my own good, it's for my own health. But I would really, really struggle. I know I'd be like, "Nothing?! Can't I do anything?!" I suppose I wouldn't be able to do, feel like I couldn't do... challenging things. Like, runs, like bike rides and things like that, like proper ones... training for like 4 months... and make yourself ill, you've only got yourself to blame. I'd like to think I'd still be able to do something. Just general being outside, like walk or something, just general... I would struggle.

It's not something I sort of forget about, it's always active in me, with taking medication twice a day, every day. It never goes, out of mind, regardless of how long it is since I've had a fit. It's been 6 months now, but it doesn't feel like that. It's not something that... It's like, going for a bike ride, it's the first thing that occurred, it's the first thing I remember, it's always there, isn't it? I don't think it will ever be different, don't think it will ever change, but... have to get used to that, really. I can't imagine it not being a factor, it's so almost, like, ingrained in my everyday thoughts. I don't... I think I said to you when I first came in, but it's not really a thought, but I know it's there. So I think maybe I don't realise it as much, because I'm so used to thinking about it. It's not something that's all of a sudden there, it's just always there. It's there every morning when I have to take my medication. It's there every night when I have to take

my medication. It's there, in the day. It's there when I'm trying to decide to go for a run or not.

10.0 Rose narrative summary and reflection

Rose was the first participant recruited for this research and I was eager to present a SWE's story. Keen to record the narrative of a SWE who was newly diagnosed, Rose's story seemed to portray the physical and psychological changes that exercising with epilepsy can create.

Presenting a narrative that seemed to change over time, the end resultant narrative type for Rose was similar to Lieblich et al.'s (1998) trial and error. Labelling this narrative a 'roller coaster,' the progressive, cyclical, and peaks and troughs of exercising with epilepsy were shown within her holistic narrative. The following will discuss the effect time had upon Rose's narrative and resultant themes, narrative type, with researcher reflections threaded throughout.

10.1 Narrative over time

Rose's narratives provided a glimpse into time's affect on a SWE's exercise experience. Within the first two interviews, Rose's exercise experience seemed quite steady. It appeared there were no apparent negative interactions within her epilepsy and exercise life expressing only positive benefits of exercise for her epilepsy. However, time was an important factor for Rose. It seemed the longer she had controlled seizures, the more risky she was with her health and pushing herself within exercise. The unfortunate result was the unexpected seizure whilst exercising, causing a disturbance in Rose's overall narrative. Being only the third seizure in her life, it caused a drastic shift within her mental attitude towards the benefits of exercise. This created a change within her narrative type as well as presented more emotional and psychological concerns for

her as she tried to maintain her exercise life (discussed further below). Such a quick change in Rose's storyline was evident of the importance of time's affect upon the SWE.

10.2 Narrative one

Rose's narrative began by showcasing the one issue regarding her identity that kept coming back, her feeling of a lack of support from her family. Discussing this in more detail in regards to her epilepsy in general, excerpts of this communication were excluded unless it related directly to exercise. Initially, she discussed her family and the view that they did not really understand her epilepsy and its connection to exercise. As this topic was discussed often during the interview, I believed that this was a topic that would be very important to her holistic story.

Linked to the concept of lack of support, immediately following our first interview, I realised that there was one theme that would be shown within Rose's narrative: hidden disorder. The first clue was upon discussing if she would talk to others about her epilepsy, she all of a sudden sank a bit in her chair, got a nervous smile, and then talked with her head bowed. It looked like she was hiding. It looked like she was ashamed and she explained that it was not worth talking to others about her epilepsy. She did discuss how she believed others viewed it, and this ran throughout each of the narratives. When she turned into this quieter version of herself, I felt uneasy. It made me want to derive more information from her, to explain why this had made her uneasy. By maintaining silence, I waited for her to feel comfortable to speak, even if I could see it was a struggle for her. I felt it made her realise that I wasn't going to drop the topic, and

I actually wanted to hear what she was going to say. This technique was used throughout these interviews and although Rose had the most controlled epilepsy, she in particular was one of the most embarrassed of the participants when discussing epilepsy in regards to her own identity.

Within this first narrative, exercise was shown as being very beneficial to Rose's health and mental state. Exercise helped her, it was positive; she never connected it negatively with her epilepsy. To increase the sense of holistic storyline, Rose's view of how her medication had an effect on her exercise routine was provided. This topic was included within the narrative to portray medicinal side effects in regards to exercise prevention and consistency, in hope to open up new avenues within research on medication and exercise.

Sport/exercise type was another theme that was shown as an important factor for Rose. Doing multiple sports/exercise, it was interesting to witness the variances between sports/exercise for a SWE. In swimming, she did not see the safety issue and would rather stay hidden. Showing this confidence with the benefits of exercise, she preferred to exercise on her own, rather than with others. However, she also did discuss her sporting choices as providing a social time and swimming was one of those experiences. Post-interviews, and even during interviews, I was going back and forth viewing this attitude towards safety as either negligent or confident. Rose seemed to not want to be scared to exercise because of her epilepsy. I was intrigued by this and wondered if it was because she had controlled seizures that contributed to this positive attitude towards exercise.

The narrative type that seemed to be apparent from this narrative was one of a narrative of progress (Lieblich et al., 1998). Exercise and its psychological, social, and physical benefits created a steady incline in narrative structure. The two were positively connected; illustrating that exercise was beneficial to her everyday health as well as seizure control.

I left this first interview perceiving that Rose did not feel that her epilepsy hindered her exercise routine in any way. I did not know what to expect throughout the year and worried that it could be very repetitive. I struggled with conceiving ways to further what she already discussed. The topics that showed through were the issues with her wanting to hide, as well as the effects of exercise for her. These interested me greatly and I wanted to see if there was a difference over time as well as a difference between sport/exercise types for Rose.

10.3 Narrative two

Rose's second narrative consolidated her previous feelings that exercise was seen as a benefit, rather than a hindrance. Discussing her struggles with sleep in great detail as well as the importance of driving, it was a goal of the interview to keep Rose on the topic of exercise. Although these topics were important to her, I felt only a minimal amount should be added to the end narrative. If it was related to exercise, I would include segments within the narrative. This maintained this research's focus on the psychosocial impact of exercising with epilepsy, yet provided me with excess information on living with epilepsy, which could be used for future research.

Within this narrative, Rose distinguished between her different versions of tiredness; physical and mental/seizure. Her descriptions explained that exercise was beneficial to her epilepsy and the increase in physical tiredness helped maintain her sleep habits as well as kept her seizure-free. Although she would discuss the benefits of exercise in great detail, she also discussed the other feeling of tiredness, which she called being “seizurey.” This feeling prevented her from exercising, and made evident that she was not ignorant in regards to listening to her body.

In discussing identity, the topic of hidden disorder became more apparent within this narrative. Deriving more information concerning this topic, Rose’s statements that, “it’s something you don’t want to have, so you don’t want to tell them,” made me realise that she did not feel comfortable with having epilepsy. It may have been the ‘Yorkshire lass’ within her that made her want to portray that it was not “that big of a deal,” but the way she emotionally discussed these topics with me, it seemed that it may help her to discuss this with others as well. By the end of the narrative, although this may have been caused by more probing and questions on this topic, her negative emotions concerning epilepsy seemed to have lessened. I wondered if she had said this to stop me from probing her for more, or if she actually believed it. Maybe it was discussing these topics with me that made her come to this realisation. I felt like a hypocrite as I knew the reasons why I did not say anything to anyone. *Why tell people if they are just going to get scared?* And I felt she was thinking the same. She did discuss that people just do not understand it and that deters her from disclosure of her epilepsy. This made me think that although Rose did not think it needed to be discussed, maybe it should, as then more

people would be educated and understand epilepsy from the first person's point of view, rather than fear the unknown.

The narrative type of progressive narrative was maintained. She seemed to still view exercise as beneficial and would provide more detail as she became more comfortable with me as researcher. Her sporting routine had increased as she began her training for her cycling event and she maintained confidence in the positive aspects of physical activity. I felt positive about her experiences, but felt nervous about what to ask for the next interview. The topic of hidden disorder was of interest to explore further, but her portrayal of exercise's effect seemed similar to the previous narrative. I was interested to see if there were changes after the Coast to Coast cycle ride, but I did wonder if she would be the most consistent out of all my participants. Being the latest one diagnosed as well as the most controlled, I wondered how her story would unfold and if this progressive storyline would continue. Time would tell.

10.4 Narrative three

The third narrative came as a big shock to me. Within the first couple of minutes, she had discussed how everything had changed through one seizure, and it was while exercising! Only being her third seizure, seizures were still new to Rose and it seemed that this event had changed things for her. Discussing how a new sense of worry and fear had developed, this new development made me wish for the old positive Rose back. I wanted her still to have that sense that exercise was helpful, not the cause of her seizures. Her mental attitude had changed and now, instead of desiring to go out for runs on her own, she desired to have company, just to "feel safe." Hearing all these new

encroaching fears vividly portrayed how impactful one seizure is for a SWE. The last 6 months, she was carefree and felt the benefits of physical activity. Now, because of one seizure, there was fear connected to exercise and even prevented it; she had lost her confidence and excitement about exercising.

Exploring the topic of epilepsy identity/hidden disorder once again, one positive that came through this narrative was her acceptance of being more open to talk about her epilepsy with others. Not only did she discuss this with her friends, but her family became more accepting and included in her exercise experiences. Hiding was no longer beneficial, she came across as more accepting of her body, and now found it more beneficial to discuss her feelings with others. I felt these were positive outcomes as a result of this negative experience.

Her emotional response to her seizure was that of frustration. Upon reporting this feeling of frustration, I felt like talking to her, saying that I knew how she felt and that she needed to keep going. Desiring not to affect the research, as I knew that my presence already had, instead I kept silent, as it was not my place to offer such advice. When she joked about having this seizure for me, I felt so strange that she was thinking of me during this time. She believed my research would benefit from her misfortune. This made me feel guilty that this was how she felt, but also interested to see if this was something that had made her more accepting of her seizure.

Fuelled by this unexpected seizure, the psychological and emotional impact on her decisions to exercise created a shift in her narrative type from progressive to trial and error, or what I term 'roller coaster.' As the previous narratives presented the peaks

of her roller coaster story, this narrative introduced a trough. This new story type presented the effect of the decision-making process in regards to exercise. Her frustration began to show and it seemed she felt stuck and envious of others that did not have this disorder. Gone was the Rose that was carefree concerning exercise.

10.5 Narrative four

This last narrative was the most interesting to me. Within this narrative the vicious cycle story had shown through for Rose. Similar to Gwen's cycle, upon having a seizure in connection to exercise, a lack of exercise resulted and created a mental association of fear and worry to exercise. When a lack of exercise built up, more fear and worry developed, starting the cycle again. Frustration developed at this feeling of how she could ever get out of this cycle. Differing slightly to Gwen's cycle, I did not find the cyclical story to have been created as a result of Rose desiring to increase intensity from missed exercise, but the fear of exercise as a result of lack of exercise. It seemed that Rose believed the lack of exercise would signify a less healthy physical state, and then she would be more prone to seizures if any energy was exerted. Discussing a before and after nature of her exercise life, it was interesting to see how one seizure had changed her outlook on the beneficial outcomes of exercise on her seizures. I could feel her pain and frustration, and wanted her to return to the old Rose. Just because it happened once does not mean it was only exercise that caused it. I felt like trying to push her to get back to who she was, but I knew I could not, and should not.

Her sport/exercise choices became important now, as compared to before; she saw certain sports as dangerous. As safety concerns increased, her whole outlook on exercise seemed to see the consequences overrule the benefits. Discussing her exercise habits with friends, now it was not only a social outing, it was a way to make her feel safe.

Exploring the topic of exercise/sport choice as well as goals to maintain exercise routine, one topic that Rose discussed was the thought that this new cycling event would positively progress her exercise/non-exercise cycle back to a progressive story. This interested me in why this self-motivation could create a change? Could motivational exercise events be a useful tool to get SWE exercising if afraid? As exercise was now more of a worry, Rose increasingly listened to her body and was more conscious of what could occur if she pushed her body too far. These new insights made me think that maybe it is seizure occurrence that makes SWE be more considerate of their body. Are we more in tune with ourselves if it is sick more often?

Exploring the topic of identity within this last narrative, it seemed that the statement, “It’s not something I sort of forget about, it’s always active in me...,” portrayed the existent nature of her epilepsy identity. Although not as hidden as before, it seemed as though Rose still felt she should whisper the word epilepsy, as she did during this interview, and through calling epilepsy an “it,” exhibited signs that epilepsy is this foreign body that lives within her. It did seem that over time, Rose became more accepting of her epilepsy identity. However, I also gained the sense that “it” will always be a foreign body living within her.

The new cyclical story was interesting as this only occurred with an increased seizure frequency. However, I believe the cycle only began because her latest seizure occurred during exercise. I do not know how Rose's story will end. It made me sad that now she had a worried, rather than a positive outlook on exercise. Time will either be an ally for Rose to overcome or cope with this new anxiety, or a foe.

10.6 Concluding thoughts

Rose's narrative provided multiple storied structures. Initially being a progressive story, shifting into a roller coaster shape, and finally becoming a vicious cycle. These twists within the story line were created over time. By the end of our year together, I felt that her confidence was slowly coming back and would hopefully lead back to a progressive story type in the future.

Rose was an interesting participant, for after two interviews, I began to doubt whether her story was 'exciting' enough. However, I quickly halted these thoughts as I realised this was a SWE's story. Exercise had a very beneficial connection with her epilepsy, and this connection had yet to be portrayed qualitatively. Her enthusiasm to share her connection with exercise also seemed to be a way for her to discuss topics that she had not discussed with another SWE before. As a result of this acknowledgement, I felt guilty for wanting to stop Rose's interviews after the second, as I thought it was too 'normal.' Little did I know that I just wanted a turbulent story. However, in hindsight, a consistent story would have been just as beneficial to current research. It would have shown the beneficial effects of exercise for SWE. Now, I feel although this story can still portray these benefits, it provides more of an example of how impactful time is for a

SWE. Only 3 months can change one's life and it is a vital variable within examining SWE's experiences.

11.0 Andrew's narrative

11.1 First narrative

Yeah, they kind of happen, umm, at our gym, we have two rooms. We have the room where you're on exercise bikes and sit-ups and what not, and then you've got the room where you're lifting weights and really going for it. We do both rooms, and there's 15 exercises in each room. Now, two years ago, it would be, you'd do that cycle twice. You go from one room to the other room and go start again there with, like 30 second break in-between. You do each exercise for 30 seconds, and you're really going for it! Coach came back to us and said, "I want us to be the best team in the country, we will do it, another routine, again." So, it's three times. And it's in that third point where I'm dying for a drink or dying for some food, it's half an hour later I've woken up and they've said, "Oh, you got to the final stage and you were three away from finishing, but um, you fell down."

I don't, I think, the last... 4 months I've had them, from... from exercise, yeah... Umm... what do I do? So, I still go to the gym sessions, but I sit out for the last session and just relax. And umm, for the benefit of everyone else, I mean, they get to carry on. It sounds horrible, in the sense that, they get to carry on. A lot of them have come up and thanked me afterwards, and said, "Thank God for that, you had one, because I couldn't carry on, I couldn't cope." And uh, make a joke of it. So that stigma comes back onto you, like, "Alright, ok, thanks, yeah, make the joke of it."... I don't know... well I mean, when they say thanks for not joining in on the end, I think it's more, umm... not piss take, but umm... some of them have said, "Thanks for having a seizure," sarcastically, joking, so they can sit out and they can go home straight away and watch Eastenders or

whatever. That's the joke they've made. And, those people are friends with me and friends with my girlfriend and we know are of a good person. No one's ever said it really, in a shit manner.

You can see a few people are worried by it and don't want to talk to me and don't want to be next to me cause, in the circuit training we go round and round from point to point. And you can see their hesitance being in front of me or being behind me, 'cause they will be the person, the first person to come to blows, so to... and... (laughs as says sentence) they won't speak to me for the rest of the evening. They won't speak to me for, uh, when I next see them on a Saturday. And uh, I have to instigate conversation with them. "Hi, how are you? Did you watch the boat race?" or some crap like that. And then they start chatting and get people I'm friendly with involved and umm, yeah, that's horrible, that's hard work. And it shouldn't have to be, basically. They should just be cool with it. But it's difficult, the stigma thing. If they've never seen it before, they don't know what they're doing. But, I've seen people change! I've seen people in the group be like that, and slowly not be bothered about it, so... (long pause)

From when it first happened when I was 18, it didn't really strike home actually because I have three brothers, massive circle of friends, and they all came together and... were a support network for me. Everyone knew each other and they all knew, it occurred. But as soon as I went to University, that's when it struck home. I was on my own, kept it to myself, and first time it happened, I got told by a very good friend of mine that people started screaming, running everywhere, and didn't know what to do. I hadn't really told people and... it's kinda like, I stopped playing... 'Cause it happened at Uni, I then stopped playing tennis and I stopped rowing, stopped swimming, and sorta

sat back. And now, I've... acknowledged the fact that I've got to deal with it. I want to play more sports, play more football, play more tennis, go on the bloody river! (little laugh) I did have one at the gym, umm, last year. I've been going to that gym for, umm, 4 years. Swimming, doing my own workouts, hadn't told them anything. And it was umm, a simple, well it wasn't simple. It was a seizure, in the changing rooms. And I fell straight into a locker and a key went into my eye. Just above my eye. Luckily it didn't go in... When I woke up in the ambulance the manager showed up and came up to me and said, "Don't worry all our staff are all trained." And he was kinda saying, "Don't, don't feel this is a need to... leave the gym. Come on back." But next week I quit the gym anyway! (laughs) I was just so scared of going back, so scared of seeing people who may have seen me. It was something like a... although they have supplied that support network, I didn't want to go back. I was too embarrassed to go back.

I've been playing football for 6 years and I've only just told couple of guys at football and... they... were.. shocked. They were just like, didn't know anything about it and wanted to know more. And we usually go play football, have a pint afterwards and that night I spent 2 hours afterwards explaining what my problem was to a group of 15, 40-somethings because they've never heard of it and they didn't know. They thought I was... fine. Thought I had a clean bill of health, so to speak. So, umm... and the guys at rowing, I should have told them. It was a stupid thing not to have done, like a water sport, not to explain it, that I could have a seizure. And I think some of them were a bit annoyed and I think some of them were a bit fine. There are a few nurses in the group as well, so they were a bit, hands on. Not pinning me down, but I think just helping me out, getting me in the recovery position straight away.

Umm, like everyone has told me to stop. And it's annoying. It's like, I can't. (long pause) I've loved sport since I was a kid and I'd always played football, and always played tennis, and always been part of team sports and if it's a new thing, I'd want to take part in it. And being told not to isn't (laughs), just isn't... This is probably the hardest thing to get involved in, the canoeing, the rowing. And me and my coach have managed to push through saying, "no" to it, have allowed me to carry on. Before no one had ever experienced it. And, yeah, it's not something I want to give up. It's too nice! On a Saturday morning, rowing down the Thames, at half six in the morning is probably the best experience ever! But when there's just a few swans floating about and you and 20 others, and REALLY quiet, it's brilliant! Absolutely brilliant. And we do it on a Tuesday night and Thursday night. Yeah, it's quite not like anything else... I'm just not going to be told you can't do that. And if I did, it would break me, it would really break me. That would be horrible. Knowing the kind of mood swings and depression I've had from random and stupid stuff. Being told that I can't do something I love because I've got that, then... I don't want to say over the edge, because then you would have to keep phoning me every day to see if I'm still alive. But it would annoy my girlfriend very much because I'd just be moping around all the time. It would probably annoy everyone I know because I'd just be in such a rage about it.

I've got training tomorrow night... It's the first session on the water in the evening so... nervous is a word that springs to mind. Like Saturday is fine, we're on the water all the time. I feel, I'm good about it. But, this is the first one where it's after work. Like, works quite, uh, stressful and uh, I don't know, we'll see how work affects it. And so, I'm going to take it easy, but they want 100% commitment from everyone.

We get constant emails from the team, the team leaders, “Everyone’s working hard, we can see they’re working hard, but we want to win the trophies this year! We have nine or ten races around the country and the first one starts, in the next couple of weeks, so we want everyone 100% for that.” Constant emails, “100%, 100%.” And then after a day at work, it’s very difficult to be 100%... So, yeah, it’s fun. But, yeah, I want to be in that boat. I want to keep my spot. I want to give my 100%... And the last couple of years I’ve taken my body seriously and taken my involvement seriously. I think that’s why the club has taken me seriously, I have the ability. I just have this thing, this wall standing in my way, and they’re helping me overcome it, which feels kind of nice.

They’ve realigned the boat, so I’m next to a nurse on my right, and the captain in front of me, and the chairman behind me (laughs). Just in case (laughs)... So they haven’t jeopardised my position in the boat, but their places. They’ve sort of given up their spot and moved people about. Which is sort of a positive thing, their commitment to me. It’s sorta, quite nice that their doing that... Some people have been pushed backwards, and I think they’ve become upset because they’ve only been pushed backwards because these people need to be around me. They’re the squadron leaders; they’re the chairman, the nurse. They know what to do if I have one on the river, d’you know what I mean? It’s umm, it’s umm good to see them doing that, but I think it’s upset a couple of people as well...

And one of the squadron leaders is a couple of years older than me, he’s been there longer than me. Last year, when I did the time trials for the squad, I pushed him out of the first team boat. And now he’s found out that I have epilepsy, and it just seems he doesn’t want to talk to me... Uh since I had my first seizure, he’s sort of taken a step

back and whenever I go to say, “Hello” to him, it’s really negative, and I don’t know whether it’s a part of, you know, it’s a part of a disabled guy kicking him out of the boat (laughs). That’s in fact the first time I’ve called myself disabled, so, that’s on tape.

Umm, yeah, I think he’s upset about that. Yeah, he was fine. And now I’ve had the seizure, he sort of is very reluctant to say, “Hello”... It’s odd. That’s the only person in training that’s uncomfortable with me being there, and being in the team, for the fact that he’s not in the team anymore. It’s kind of strange...

Coach’s seen that I can get on the team and I can provide that extra little power in the boat. So, he doesn’t want me to quit. It might sound selfish on his part, but I think since it’s his boat, he wants it to be really good. He’s told me where to go and get, umm... certain... buoyancy aids that won’t restrict my rowing. But I have to wear them all the time now, he’s just told me the other day that I can’t not wear a buoyancy aid in the boat. But he’s helped me find some that will turn me over in the water if I fell off the boat. And keep me upright, so it’s kinda cool, keeps that, part of me feels I’m okay.

Umm... it kinda does because you’re on a boat with like 20 people and you’re the only one wearing one, and you just think people must think, “Why is that guy wearing, why is that guy wearing a... buoyancy aid?” But umm, yeah, I don’t have an answer for that. I haven’t even thought about it. I think about everyone in the boat knows why I wear them, so, I shouldn’t have to explain to everyone.

I think that’s, me and my brothers have always competed with each other. We are all close and have always competed to be the best at certain things. And when you aren’t the best, you sort of get embarrassed. That’s...this has made me, kinda not the

best, but I want to BE the best. I want to break through the stigma and I know the people are there to help.

Well there wasn't anything umm, to do with it, sort of, you know... all the websites just said... "Don't swim, don't go near water sports, don't do this. If you're riding a bike, make sure you've got somebody behind you," blah, blah blah. All the obvious stuff you would think of. Not, "Oh there's a group for this, there's a group for that." No one suffering from it, putting their story in there and an expert coming back and saying, "Totally agree with you but, perhaps you should try this." Whereas the American website has massive forums, explaining their stories, and allowing experts to come back. And, there's people out there like you! As soon as I read them, I was like, bloody hell, there's a continent on the other side of the Atlantic with loads of people suffering from it. And in Great Britain no one, said, seems to have the problems I've got!

It's sort of taken me, 10 years, how old am I? Yeah, 10 years to sort of mature and know and accept that I've gotten it, and try to look for answers and key questions to ask people. Before it was, I'll keep on smoking, I'll keep on drinking, I'll keep on taking drugs. I'll keep on doing this partying, whatever. And deny any knowledge that I've got it. And that must have been frustrating for everyone who knew me! 'Cause they were like, "Calm down, take it easy." Yeah. And uh, it's only in the last couple of years I've kind of stepped back from myself and said, "Oh my god. What damage I may have caused people." It's scary, very scary. And I don't want to admit it. I only, I've only admitted it to you! (little laughs)... And it's uh... God the amount of people who would have loved to hear that!

Tegretol²¹, the day I started it, almost felt like a new beginning... And I was still on the, the... previous... Lamotrigine²²? I'm still on that with Tegretol, and felt like a positive man... And a new buzz and more energy and stuff. They decided to swap Lamotrigine for Keppra²³ and I started getting, like my mouth was falling apart and I wanted to punch everything that walked past me (laughs). Didn't help in the boat, at all! And didn't help at football at all, 'cause I was going in with my feet raised and trying to take people out. And, upsetting a lot of people and my brothers were always getting upset. Umm, depression, really bad depression. If I lost a race in the boat, I would sink into this, this, "It was my fault," sort of, and "Why didn't I score another goal?" Really difficult to explain to people. Really difficult to explain to my parents how I felt, that I wasn't achiev-, I felt I wasn't achieving. And so, a few people I spoke to, a few chemists said, "We've done a little bit of homework and perhaps you should try taking vitamin B supplements and zinc." I've been taking them for 2 months, and it's changed again...

11.2 Three months later- Second narrative

And it was at the same time, that my specialist decided that Keppra was giving me too many side effects and decided to give me Topamax and that's given me even worse side- effects.... I don't know. I ... I don't know. I have no idea why... But I do know that drug has changed me.

I can't, it's just peaks and troughs, peaks and troughs. And I haven't recorded it cause since then my life has gone through... through some really weird stages... And this drug, stresses you anyway. It makes you quite angry and quite a little bit annoyed with

²¹ AED

²² AED

²³ AED

things. And the specialist said, “Don’t get into situations where you can get stressful, so it’s probably wise that, if you play sport, don’t play physical sport.” And so I said, “Do you want me to tell you what I do?” And she’s like, “Go on then.” I said, “I row.” And she said, “How many people? What kind of rowing?” And I said, “Well there’s 20 of us in a boat.” And she said, “Oh, I’ll probably give it up.” “What?! That’s the one thing that made me positive and really made my life good and you’re telling me to give it up?” I took my brother along and my girlfriend along for a bit of support and I got quite angry. And she said, “Look, you could put people in, you could get annoyed by this,” blah, blah, blah. Umm, football I had to give up because it’s in * and travelling there and back is dangerous, so she said, “Give that up.” Two things, sporty things in my life that I really looked forward to each week, three sessions a week, that I really liked, have completely disappeared. So I’ve had to try to replace them and it’s difficult when you, when I was alien to this area of London and I’ve made these sports, and now I’ve got to try to make new sports.

I think I’ve been scared a lot this year by, not by myself, but by my friends and family and stuff about my life and the risks I’m taking. But then, what do you do if you don’t do anything? What do you do? It’s a more boring life? Sort of all said, “You’re 28, you’re going out on a row boat, you’re swimming on your own, you’re going to the gym on your own. You’re doing this and you shouldn’t really be doing that.” It makes me think, “Yeah, maybe if I do go swimming or the gym on my own, maybe I should go tell someone?” But I don’t want to tell someone that I’m swimming because then I have got to have some idiot watch me swim, and I don’t want that.

It got to June, and, I had to say to my rowing people, “Look I can’t go on. This is, I am almost endangering you by me being so worried all the time.” And I’m being negative, and they were really good, they were really... They were like, “No you’re an active member of the club and you have been since you joined.” And some of the people who didn’t even know I had epilepsy would kind of be like, “We didn’t even know and you were still really positive about it.” And the people I was close to were just like, “No, fight for it.”... But, it’s like a... community that I kinda lost. I still see a few people around, a few of them are friends. I got invited to, you know the rotary club people? They do a charity rowing event, and one of the, one of the crew asked me, he was going to put a boat together to raise some money. And said, “Would I join his club? Would I join his crew?” And he did tell me, like, he was going to invite other people from our proper, like, rowing club to come along, and they were surprised when I turned up, it was like a “Welcome back Andrew.” It was quite good! (laughs) Like all hugs and stuff and, “When are you coming back?” and all that stuff. “When are we going to see you in the crew and stuff?” I kind of gave them a date, like August (laughs). But once you get out for more than like 4 weeks, you lose your nerve to get back into it as well. I don’t know. Confidence is gone I guess. But, I could do it... I could get back in the boat with the proper club, and there is a lot of support there. But they’ll also want me to be, you know, 100%, knowing that I’m not going to kill myself, I guess... And I just said, “I’m going to wait. I’m going to see if I can go seizure-free for as long as possible,” and coach understood that. I just thought I’d build up a confidence... But coach understood... I’m young, I’m fit, I can get back in the boat. If I keep myself fit, if I go for a run, push myself to keep fit, I can go back to the club anytime.

I've quit the gym. I couldn't be bothered. I just thought "No," I didn't even want to bother, so I stopped cycling. I'm AMAZING at thinking at... if someone says, "Imagine if you're cycling along and you have one while you're cycling." I'll compute what they're thinking in a matter of seconds of my jaw hitting the floor and going into the curb and that's it, I'll stop. My bike has now been in the shed and not been used for 3 months. Whereas 3 months ago, it was being used every day. Three months ago also falls in line with me starting this drug. Now has that placed some fear factor into it?... I don't know. But, it's... all things that I have liked have all finished around the time that that was introduced... I'm missing my sport...

I try to exercise three times a week. Play tennis with neighbours, they're not competitive, they're quite lazy tennis players. They stand in the middle of the court of the other end and you have to... run. And I play with my little brother who's more competitive once a month. So, tennis, twice a week and running about three times a week. And just, normal weights, but that's just in the house. So I've gone completely from any like, social, like the gym, I left the gym and taken it to my house, and started, I guess I picked up sports where you can't injure yourself as much as possible. If that makes sense? ... My sports, when I was younger, were BMXing and downhill mountain biking, and now it's gone to lifting a weight in a bedroom. It's kinda like... but, if that's what it has to be, that's what it has to be until there's a cure.

If it's a Thursday night game in football, or a Saturday morning run, then I'll do it. But if I've been stressed, I think I know now that stress is a cause for me to have a seizure. So, I will now call everything off and chill out at home. And that will be me, taking everything out, social activities out, going to London, I will just call everything

off. And that's something I've done this year as well. Just, I used to always attend as much as possible try and attend, if someone's going to the pub, I'll try and be there. Now, if I don't feel up to it, I'll just say "No." Which has really been difficult, because my social calendar has just been dead (laughs). Non-existent! Really bad!

I don't know. It's because my seizures were usually always in the morning, when I first woke up... And now it's come around and I'm having them at night, and I don't know why... My stress levels have gone up because I'm not exercising. I don't know whether that's... I was always exercising in the evening. I don't know whether that's changed it for now.

Recently, I have been telling people I have epilepsy almost as soon as I speak to them, which I think is as a result of meeting you. I don't know why... People at work have noticed it, that I've been more open about it and like telling people and it's kind of helped our clients. Because our, I knew more about epilepsy than our clinicians... And umm, yeah, I've been more open with it there and when I've been going out I've been telling more people, I don't know why... People, when I was younger, mentioned my epilepsy, I used to get really upset and walk out and cry or whatever. And it's kind of, I don't know, the stigmatism that I thought was attached, hasn't been. And I've taken part in a lot more activities with Epilepsy Action as well. I'm more actively taking part on their website and taking part on daily activities and meeting people suffering and going along to their... you know... don't know what they call them... yeah, meeting group type things.

I'd like to go a year without seizures. Umm, the, my main consideration is driving. That was the biggest shock. And I only realised this year that it's been 10 years of having seizures and that was a really big kick in the stomach, and I didn't realise it... But, I hope it would be a year before I would take up all the things I've lost. People say, "Oh, you can get by without a car." But not just getting by without a car, but get back confidently on the river and get back confidently on the bike, and that is not just my confidence, this is for my girlfriend as well. Knowing that she will be in the flat, feeling fine. 'Cause, you know, I used to come back, bike home and she would be by the door, waiting, knowing that I'd be home at about 6 o'clock and she'd be like, you see that sort of nervous sweat and a sort of breath of, "You're alright? Good, we can continue." And when I haven't phoned that I'm going to be late she's trying to phone me, "Where are you, where are you, where are you?"... But, I've told her, to calm down, I think I know my limits. But the environmental factors of like, travelling on a bike at 25 mph isn't very good, or travelling on water, or swimming in water or, those sorts of things. I mean, running on grass, playing football, think are fine for both of us.

11.3 Four months later- Third narrative

I saw a nurse and she said, "Stress, just take it out on stuff that you like doing." SO, I came back from Christmas having seen my younger brother and he said, "Run! Run as much as you want, take it out. Stomp the floor!... So every step you take, see the people that you don't like at work or see epilepsy written on the floor," and I've done it, and it's amazing! I put my favourite music on and I run. And I've never been a runner, and run around the block more and more. You were a runner. Me saying I run about 2 miles is like nothing. But to me, I could never run 2 miles, and now I'm running and

doing it three, four times a week. Feels awesome! Might go running when I go back. I'm trying to be as active as possible, and every time I do it, I'm taking those words my brother said and, almost take your anger on it and you'll feel a lot... He said, "Take that idea, take that theory and you'll feel a lot better." And, it seems to work... I tried running last year, and I ran for a week, and yeah, nothing. And now, I run in a 10 year old pair of trainers, for a month! Consistently, four times a week, and I love it! I think it's just brilliant! In the lycra trousers, the stupid hat, and an orange top! I look like an idiot.

But yeah, so that's basically how it's been. And what else... tennis, I'm playing a lot more tennis as well, even though it's cold... And skipping a lot, which is annoying, because I'm on the ground floor of an L-shaped block of flats, so everyone's looking down, and I skip in the garden... Yeah, skipping rope. I skip proper boxing style... I do get some odd looks of people going (pulls a face) and I do that before my running and then I go off on my run... yeah... I've become a bit more... (pause) I'm liking the idea more, sort of, of running. I do different styles of running. Tiptoe running and hold my hands out in front when I'm going up hills, to make it a bit harder. Try to touch my knees, bring my knees up to touch my hands. Past all these people with their windows open, and they're all eating dinner and they see this orange thing going dancing everywhere... It is quite funny, amusing them and stuff...

Uh, I'm going to start playing football again in the summer. And that's a Sunday football, thing. When you say increase it... that's what I want to do. I have to reach a peak of physical performance before I even think about doing that. People are already commenting on how well I look. Only men, kind of scary. So I might go back to just eating lots of chocolate!

I've got the neighbours running with me, yeah, it's brilliant! There's about six of them. One guy can't run because he's got dodgy knees, he bikes alongside us and helps us or what not... I think they wanted to do it because they were all old and I wanted to do it just because I wasn't allowed to do my rowing... See that's why I tried to get more people running... I think that was my intention, to get people more interested in running... umm, and therefore if Rachel²⁴ can't run with me, I can call on others.

At the moment I try to optimise myself and I just, and I'm enjoying it too much. I think... all these things that I used to... I was turning into a cabbage! Does that make sense? Alright, not do this, not do that. Not go out, sit at home and watch telly for 3 hours. I now go home, go for a run, clean up, do some extra stuff, and by that time I can eat, and I feel great! I feel better, I take my medicine an hour earlier usually because I'm out on a run. Umm, but, I haven't thought about not doing it... It's an exciting time cause I, this time 2 years ago, I was severely depressed. Not wanting to do much. I had the dragon boating, but there was nothing much else. Not much stimulus in my life, external... I was sort of crazy, now I'm sort of pushing myself... and I wanted to do it just because I wasn't allowed to do my rowing.

That's the other thing, I asked to go back into the rowing squad and they said, "Yeah, yeah, it will be fine"... I've emailed them and I've said, "I'm getting healthier again and fitness, but, BUT, what I want is to see how my new medication is working, and I don't want to put anyone in jeopardy in the boat." I would like... I know it's a stigma that sits above your head and I know that 12 other people in the boat will be

²⁴ Pseudonym for his girlfriend

thinking about it, and I just don't want people to think about it. I just want to go 6 months-... a year without a seizure, first! Before I even go near the boat.

I just don't like the stigma. Umm, I see disabled as the stuff my sister has. That's disabled... That's disabled. She's in a wheelchair, 24 hours a day. But that's disabled, I'm not disabled, I can, I live partially, a free life. I have a rare neurological disorder which makes you fall on the floor, and I don't think that's disabled. However, I do sometimes use it to my benefit... So yeah, putting all those things down I would classify myself as disabled because I get all those benefits but, it's... I don't really like to be. I still think there's a stigma that I'm trying to damper... I think it was mid-20s that I was HATING the idea that I was and I would, if I was called it, uh, I felt I was painted with a brush, and would head to the nearest pub. And then have a seizure, after drinking loads... I haven't done that for, for ages... no, I never tick the box. I just, take the benefits.

11.4 Three months later-Final narrative

February... when I saw you in February I hadn't had a seizure since December. And then, that continued through to... May? So, it was a really, really, big remission period. My doctor, my specialist was really happy. She was saying, you know, "This could be the year." Bigging everything up. And... umm... and then I had one. And, it just put a downer on everything. In that period, every week that went, I had a massive wall-chart. A wall-chart on my wall at work, and wall-chart at home. And highlighting each week that passed. And my computer which is linked to that, which is linked to my Mac, and to my mum and dad's computer, so they could see. (laughs) God, it was

getting ridic-, thinking about each week that goes... I think I got to a stage where, I think it was, that night where I had the seizure, I went into my brother and said, "It's been 6 months." And he high-fived me, and it was a sort of coming of age type thing. And I went and went, "Yeah! What should I do?" I could go and go down to the pub, but I can't go to the pub, well I can, but... So I thought I'd do some exercise... thought it was the best thing to do... And, umm, I was getting a bit more confident in everything I was doing. I was running without telling people. I was doing a few more activities at home that I don't think I should have been doing, and... I really pushed it. I went for a run and came back, did loads of weights, did loads of press-ups, sit-ups. I've got one of those hanging chin-up bars, did that. Went for a mini-sprint run, came back and woke up in bed. I remember coming back into the room and woke up and... the trail of blood from my bathroom into the bedroom. And that... 'cause I can't remember what happened. Umm, all this side (left side of body) was completely dead. Really hurt. Shin, really swollen, massive cut down there. Umm, but this side of my head (opposite side) was really dead as well. So I must have fallen on that side, and went to that side...

While exercising, I do feel weary. I do feel light-headed, I've never had a halo... And I've never had one until the evening of course when I had one. And I just sat down, took 5 minutes, breathed, stretched, carried on and had a seizure. (laughs)... We have a mirror on the wall. And I was doing weights like that, (above head) and as I got to the top my head felt a little, umm... not light-headed, you know sometimes you see stars, ever seen stars? And I just put the weights down, sat down, looked at the telly. Got up, looked outside, made sure everything was alright, sat down and carried on... No, I just... took it as I'm feeling... It felt like I was alright. I drank one of those protein shakes...

And then everything was fine, went for another run, and came back and then woke up in bed... And that's the first time I had that feeling. But that is the longest I had been doing loads and loads of sit-ups. As many sit-ups as possible... I thought, can I do 50 (laughs) without falling over? And I did 25, and I got to 100 and my stomach felt like it was about to collapse... and that day I met this guy, from work. And he said, "Do press-ups where you push up and clap." So I did like, 50 of those. And he gave me this rubber band thing where you shut the door and use it, like to mimic the stuff you'd do at the gym and... thought this was going to be AWESOME! Dripping with sweat and went for another run and then... the rest is history.

I just went into an all-time zero. Really depressed, really... it's almost about 3 weeks ago, 4 weeks ago. So I stopped everything, stopped it. Said it was too dangerous. Everyone said to carry on, I said "No." So everything went under the bed or in cupboards or shoes put away. I said, "I can't"... I got the games console out. (laughs) I don't play on the games console at all. And then, it was so sad. And then, I realised what I was doing. I was sort of, closing the curtains to everything. And I thought, "No I can't do it. I need to get back out..." But it was just a REAL kick! When you go that amount of time and you think that's it.

And then... in that week where I was really low, I phoned my brothers. I phoned one of my brothers who lives further away and told him how low I was feeling and he... umm... he broke down on me and said, "I've never been there for you." I've got three brothers. And the one who lives here, because I work with him and stuff, he's like the mother figure. He knows everything. And he works in sort of medicine, so he knows people... The one who lives in* is sort of detached, and now he sort of wants to

understand what I've been through. And sort of brought us together. So he's joined (laughs)... joined Epilepsy Action and he wants me and him to run the marathon next year. So he said, "You're not giving up on all your sports!" So he started training as well. He wants my little brother to start running around the parks. He wants the fattest brother, who lives here, to start training as well. So the four brothers are apparently going to train and do... some good off the back of someone, as he says, "Who doesn't give a toss"... to keep me going. So I thought, "OK!"... So he wants me to... he's like "You're not going to give up. Keep running. Get your girlfriend to keep running with you. Don't eat too many biscuits or donuts." (laughing lightly)

I'm beginning to get my confidence back... just started for a couple of weeks. You just feel so much better... My specialist says, "It's good, keep doing it."... I'm still doing the routine, but umm, cut down, slimmed. Call it slimmed. I run around the block, but not as far. Not as many circuits and then come home and not as many weights... I want to do more and I think I'll build it up. I won't push it... I do, I do about half... Kind of about half hour to 45 minutes of running and jumping and skipping and.... No, it's still less than what I was doing before...

How I decide to exercise?... Well, the first thing is, are the neighbours sitting outside? If so, 'cause they are all fat, I do it to make them all feel real bad. (laughs) That's the first thing. It does, because half of them go inside... It's how many people I've argued with I think, and if I had a sort of successful day... Remember my swear step thing? I do it now with, I have it in my head, and I have that person in my head and I have swear words and then I just fire swear words! It's brilliant! (laughing)... With running, because we want to move from rented to try and buy a place, umm, I run and

try to see as many sold places and map them in my head and run again and see how many new places. And then I get back home and go, "I've seen three sold signs!"

Full stop, I think exercise... it helps... No, I wouldn't stop again... Don't think so. Difficult I think. It's obviously the emotional, what it does to you, when you're, how you're feeling when you go into those appointments, and the specialist tells you certain things. I was expecting her to tell me certain things like, "You should..." But, if someone told me you should stop exercising 'cause you had one when you were doing a sit-up... Because it is, you're confining yourself more and more. The walls are really pulled in and what else can you do? She's the one who suggested I just play safe sports. And she listed a load of safe sports... So, I'm sticking to those boundaries, tennis and running, stuff like that... Umm... ruled out cycling and... I hadn't, I rode my bike the other night, and it was lovely. That was the first time I had been on it for a year... so Rachel said, "We'll go and do some more cycling, bike ride round a park, do some light trail biking and things like that, on grass"... Saves me falling off and hitting a curb. I'll just fall in deer poop.

Uh, yeah, I'm going swimming this weekend, at my parents'... No, I don't worry... because I've swum all my life... When people say to me, "You should worry about it," I'll tell them to "Sod off." 'Cause my parents have a pool and it's a... (pause, looking for a word)... it would remove part of my life. That's what I said to my girlfriend once. If someone told me I had to go swimming with someone, all those memories of swimming on my own... does that make sense? I used to swim at the gym. And when I had a seizure there, I stopped. Just because it is so... the swimming pool is through a load of corridors and you realise, you are on your own. When I had a seizure,

I stopped my membership, said “I don’t want to go there.” It just woke me up, I just realised, I could have had it anywhere in the gym. Could have it in the lobby into one of the machines or in the showers, or in the... and the people there aren’t nice attendants... Umm, but swimming, we went swimming... in March when it was quite warm... and my girlfriend said, “Are you worried?” and I said, “No.” And she took that as, “Don’t ask me again.” I think that’s the best thing. I like it. I like swimming on my own when I’m at my parents’. I like swimming in the sea... I just think it’s... I kinda know the times where I’m going to have a seizure. Evenings, and all the last ones have been in the evenings. I’ve never had one during the day, unless I’ve been... umm... really, really drunk or doing something silly. So I don’t see why someone should swim with me. When I go home in the summer, I ask my girlfriend or my parents or brothers to go swimming with me, in the evenings. That’s the only time I don’t trust myself.

Exercise... empowers me. It... (looking at question)... umm... don’t know. I find it... like I said, sort of empowering. In moments like this where I’m going through a stage where... I’m feeling good about myself. And I think, that’s my problem. I should stick to a steady plane of how much I do and how much I stick to. As the time ticks by and I don’t have a seizure, I increase and increase and think I can get away with more and my exercise amounts go up. And the time spent running goes up, cause either I get fitter or I feel better and what not. And I think I shouldn’t ’cause I must have a threshold, it must be something like that because I’ve always dropped while I’m at rowing or during exercise. And, but it’s never been measured. I’m alright doing like, 45 minutes of light exercise. So I should stick to that and maintain it ’cause I still feel happy, I still feel good, and still feel sure about myself. And a couple of hours playing

tennis is fine, I can get away with that... I think exercise has got to be done or otherwise I go into a state of there's nothing else to do almost. Try to be active and if you're not, then, you work, rest, play video games like my neighbours, and just... boring... and I was talking to my younger brother about it yesterday. I don't understand people who... I'm hitting 30 in a couple years time, and I don't want to be creaky by my late 30s... And I know, all my 20s, I've abused myself. And if I don't start keeping, like, an exercise regime now, then I'm going to be in trouble... I'm not exercising to look good. That's not what I'm trying to do. I want to feel good. And I do feel good! I feel like I've got an extra litre of air in my lungs! I don't know, it just must be done. If I don't do it, I get depressed. There's nothing else to do, apart from, wake up in the morning and go to work, which is sad.

I think that's the patient's prerogative to take it by the grip, and grip it! And, not to try to find out a reason, but to live as healthy and to... get all the negative factors out of your life and just continue as normal as possible.

12.0 Andrew narrative summary and reflection

Andrew's narrative presented the constant changes that epilepsy can create in a sportsperson's life over time. Each interview portrayed his physical and mental changes caused by lack or increase in exercise, as well as outside variables, such as medication and social support advice/support. I felt quite lucky to have been able to witness his story for this research.

Analysing Andrew's holistic story, a roller coaster like pattern presented itself as the form of his story. Similar to Lieblich et al.'s (1998) trial and error narrative type, there were ups and downs over time, each peak or trough coinciding with an outside variable (e.g., medication, medical advice, social support, sport/ exercise type, etc.). The following will discuss the importance of time in the formation of Andrew's narrative, followed by a discussion of each narrative individually with researcher reflections.

12.1 Narrative over time

As seen in the other participants' narratives, Andrew's story evolved over time. Each interview presented a variation within Andrew's narrative, as every 3 months, changes in Andrew's exercise and epilepsy life had occurred. These changes were caused by variables of; changes in medication and the resultant side effects, seizure activity, exercise/sport type, and medical advice. Presenting these ongoing changes in a SWE who has had epilepsy for 10 years has yet to be shown within research. Portraying these narrative shifts depicted the importance of using narratives for the SWE. It is hoped that through telling his story, time's impact on exercise life can be shown and as a result, successful coping strategies can be developed.

12.2 Narrative one

Coming extra early for this interview, Andrew seemed eager to talk. Calm, yet lively, he seemed to feel at ease from the beginning. Within this first narrative, the theme of stigma came strikingly through. Analysing the narratives, this felt to be one theme that was very apparent in his story, and a topic he dealt with constantly. I began to question, what could make his stigmatic feelings so strong? Not only was he the only man in this research, but he was also the only one that had participated in a team sport, i.e., rowing. This may be another key aspect of his heightened sense of being different and not wanting to discuss his epilepsy.

One clue to his heightened feelings of stigma was that Andrew seemed to feel other's perceptions strongly. Thinking that maybe this was more in his head and his own embarrassment projected onto others, I asked for examples. He seemed emotionally affected as he discussed that the others in the boat did not all talk to him. Whilst talking, he seemed disturbed by these events, and by constantly repeating that it was not such a big deal, yet continuing to provide examples, it made me think that it was an important topic to him, although he was stating otherwise.

Social support was key for Andrew. Revealing a strong close support system, I felt he had people around him that really cared about his safety, as well as wanted him to continue to live as much a normal life as possible. However, although there was this social support, he was still left wanting. Desiring to hear other's stories, he sought to find others like himself. He expressed his frustration with the medical help and advice provided, as well as not being able to find access to others experiencing the same issues

within England. In his search, he discovered help outside of England, within American epilepsy chat rooms. Being able to read other's experiences on the internet made him feel not so alone with his epilepsy and exercise troubles. When I heard this I thought, "Yes!" This is the reason why this research is being completed, and this is the reason why he is taking part. He desired to help others by telling his story so that in the future, there will be something out there for people like him. Others sharing a similar experience will be able to read his story and see that they are not alone, and possibly use his story to aid their own exercise life with epilepsy. My one question within this aspect of Andrew's narrative was, why does England not have this support aspect yet? Was it the heightened sport culture within America that caused it to have these resources? As a result of this thesis, no longer will SWE in England feel alone.

Identity was another topic drawn from Andrew's first narrative. Andrew seemed to portray two different identities: hidden disorder and athletic identity. Not discussing his epilepsy, even in safety situations (e.g., in a boat or swimming pool), Andrew would rather stay hidden than reveal his epilepsy to others. Although he felt more accepting of his epilepsy now compared to when he was first diagnosed, Andrew explained that he would rather never go back to the gym than be stigmatised as the one who had the seizure in the locker room, and people now fear. I found it of interest to discuss his changes in exercise habits because of embarrassment or people's reactions. Not only did this show Andrew's hidden disorder aspect of his identity, but also felt stigma.

Andrew's athletic identity seemed very strong and describing that being told not to exercise would "break him", really struck a chord with me. I felt this showed how much he loved to exercise, yet I also feared for the future. What would happen if he was

told not to? How much would that affect him and what would be his emotional response?

Although Andrew seemed to not have much acceptance of his epilepsy, he did show some acceptance as he discussed having to now listen to his body compared to pushing through activities. For example, this was shown through his understanding that he needs to stop before the last round in circuit training. However, I wondered if this was because of physical acceptance or more because of the fear of embarrassment as well.

Expressing issues with medication side effects, I was able to witness how much the behavioural side effects had interacted with his sporting life. This topic has yet to be shown within current research on epilepsy and sports/exercise. In discussing negative emotional responses as a result of certain medications, more exploration can be done with others in future research.

After this initial interview I was eager to see what would happen next. He was a very captivating participant and this was heightened by how he seemed to fight his epilepsy every day. It still seemed a day by day and week by week experience for him, and I was intrigued to see if there would be more change or consistency over the next year.

12.3 Narrative two

From the start of our next interview, I had realised something had changed for Andrew. He seemed very tired, had speech delays, and kept forgetting what he was saying. He was no longer energetic and excited. Soon after he began the interview I

realised why, he had changed medication and discontinued exercise. When he told me how much his life had changed in the last 3 months, I could not believe it. Not only was he now what appeared to be a ghost of his past self, he had no more drive or confidence to exercise.

The first striking aspect of this narrative was the neurologist's advice to stop exercising. When he said this, my heart sank. It seemed counter-intuitive to advice within the literature. I was always quite pleased to read new advice about maintaining exercise habits within research, as I was given similar advice to Andrew when I was younger, and knew how damaging this could be to one's health and mental state. Although he was eager to control his epilepsy, resulting in trusting the advice of the doctor, I also felt that maybe he should trust his own instincts and maintain his exercise routine. His resultant feelings of a dead social calendar, becoming a recluse, and feelings of low confidence to exercise, were the result of this advice. I wondered if his neurologist knew how much of an impact these words of advice had made.

The resultant low confidence and hesitance to exercise, created troughs in the roller coaster pattern of his story. I was saddened to see such a big drop and wondered how or what could trigger him to climb up again. His main goal was to maintain seizure control, and get life back to 'normal' without seizures interfering, and as a result he was determined to do whatever to achieve this.

Although Andrew expressed a feeling of depression and inadequacy, he also reported a good support system, even whilst not exercising. For example, he had the support of his old team, eager for him to return. Knowing this seemed to allow him to

see that he was not forgotten and although he had these seizures, they wanted him to come back. He seemed quite lifted with these remarks, and I could tell from his smile and excitement on his face that this was a perk compared to the not so wonderful last couple of months.

Upon exploring different sports to try, swimming became an interesting topic for discussion. Andrew felt that swimming was not something that worried him and that he would not tell the lifeguard he had epilepsy. Although I sympathised with Andrew, I also could see the possible dangers surrounding such an attitude and knew this would be a topic to return to later on in other interviews. As his attitude was connected to his hidden disorder, I thought this would be important to continue throughout the year and see how it changed or stayed consistent over time.

Although he felt more hidden in his ability to take part in social sports, he did surprise me when he discussed how more open he was to becoming not as hidden in his epilepsy identity within everyday life. This was interesting, especially after hearing him discussing his non-disclosure whilst swimming. Andrew had become a part of the epilepsy community. I was surprised when he stated that he thought I was part of that change. Maybe it was because I was open with my epilepsy on questions he asked. Or, maybe it was just the fact that I am undertaking this research and have epilepsy. I don't know. I was happy to hear him become more accepting and desiring to have epilepsy known to others.

Talking to Andrew always caused me to hold my own emotions in check. As topics close to my own state of mind would be discussed, I had to maintain the

researcher role and question, rather than comment. This caused lots of angst within, and always made me wonder if I should give advice, rather than just listen. I knew I was not in the right authority to provide advice, and questioning his actions was the one way to get him thinking without providing advice. Lots of discussion with supervisors and reflection would occur after interviews with Andrew. As a result, I felt stronger and more confident as a researcher, yet also grew as a SWE. When he would state themes or topics that I struggled with also, I could now see the outsiders' point of view. *What is the harm in telling the lifeguard? Who cares if you are watched like a hawk?* These questions and comments would be stirred within me and I have realised that not only have I had some affect on Andrew, but he has had an affect upon me as well.

By the end of our interview, I came away with the feeling that he was playing a waiting game. It seemed he strongly desired for seizure control, and he would do anything in his power to achieve that. If this meant not doing any exercise, then that is what he must do. Although he thought that extracting exercise from this daily routine would help his seizures, I felt that the positive effects of exercise for Andrew were not yet accounted for. I was intrigued to see if this became more apparent over time. Maybe his seizures would increase and a clearer picture of the possibility that exercise did have a benefit, or was counter-productive would present itself. Interested to examine and track this over the next 3 to 4 months, I was impatient to see what the next months would bring to Andrew's exercise life with epilepsy.

12.4 Narrative three

By the start of our third interview, Andrew had surprised me again. Another changed man! Energetic, lively, he seemed to be happier with his life. He still had symptoms of medication effects interfering with his thought process, but he did not seem as upset about it as in our prior interview. Whilst discussing his recent 4 months, I realised the change was linked to his return to exercise life. His change in attitude towards exercise was shown through the confidence and excitement about exercising on his face as he talked about what he was now doing. This was such a change from four months ago, and he seemed much more upbeat about life. The key to this new peak on his roller coaster was his social support system. Mentioning the affect his brother's attitude and words had upon him returning to exercise, I was interested to witness more. Not only was this outside push to exercise from his brother, but he continued to be less hidden and encouraged neighbours to exercise with him. This created confidence again in his safety whilst exercising, as well as provided a social activity, something that he was missing from the previous narrative.

Although he felt more confident in his exercise life, returning to rowing was not yet in the cards. Discussing that he did not want to jeopardise others, this stigma came back at me. He did not feel confident enough to row and possibly have seizures, yet he could run with his other social network. I wondered if it was the safety of not being on the water, compared to being surrounded by people on a boat, with their reactions, and how they would deal with a possible seizure situation that encouraged this hesitancy.

Discussing identity and disability, being labelled as disabled was a concept that Andrew strongly disagreed with. Linking to the invisibility of epilepsy, he discussed that he did not consider himself disabled, although he inadvertently said he was within the first interview. I questioned why not, and what his view of disabled was, and it seemed to be a very stereotypical old-fashioned view. It was physical, viewable, and highly non-functional. I realised that this was most people's view of disabled, and when he discussed it, I flashbacked to my own issues with this label. Questions that kept returning to me were, how he did not think he was disabled, yet he was not physically capable of rowing safely? His actions were limited and his epilepsy affects his daily life, this by law definition is disabled (UK Disability Discrimination Act, 1995). Re-reading his narrative brought these themes to mind and brought out the theme of the hidden illness and its connection with the disabled identity.

Following this interview, I was eager to see what the next 3 months would bring to Andrew's life. Every interview had been different and his roller coaster story was up and down every three to four months. Time had such a strong effect for Andrew and I desired to see if this would continue. Eager to see the possible continuation of the importance of social support for Andrew and his exercise life, I was intrigued to see if this would be a heightened positive or negative, or both!

12.5 Narrative four

At the beginning of the last interview, Andrew did not seem too changed. So, it came as a surprise when he told me of his recent seizure and subsequent confidence loss in regards to exercise. This sudden trough in his roller coaster experience with exercise

caused my heart to sink. It had seemed he had gone backwards and I wanted him to become confident and enjoy exercise again.

Over the last 3 months, Andrew was becoming more confident in his seizure control levels and exercise. He then began to push himself more, began exercising without anyone, and then he had a seizure. This caused a relapse, creating hesitancy regarding exercise. Within this trough, he seemed to have returned to his former self, hesitant and watchful of his body. However, tying into the key theme of social support, with his brother and doctor's support, he seems to have been able to increase his exercise levels. With the help of his social support system and his description that he does not want to be a slug or confined, he wants to exercise, an upward shift in his story had returned. Now, he was making safer choices. I was intrigued to see a change within the doctor's advice regarding exercise. I wondered, what possibly could have changed this, yet he did not know.

Continuing to become more accepting of his epilepsy, he discussed the benefits of listening to one's body to be able to exercise safely with epilepsy. This topic was discussed in other participants' stories as well, and is a developing theme in regards to safety and exercise. Although he described a greater concern with listening to his body, however, in regards to his safety whilst swimming, his athletic and epilepsy identity took over, thus refusing to acknowledge a physical limitation in regards to swimming. Still not accepting of the dangers within the water, he felt that he would not be willing to be told not to swim, nor tell a lifeguard. This worried me and I wondered what would make him change his mind. He has had seizures whilst exercising before, just because

he is a confident swimmer does not mean a seizure will not occur. He seemed to realise this, yet did not want to change his mind on the topic.

Crucial to Andrew's exercise story was his final words on the benefits of exercise. Andrew stated that exercise "empowers me," which was very telling of the importance of exercise for Andrew. Taking away this final statement, I realised that this was a topic to consider for medical professionals providing advice to their patients. Not only was exercise helpful to health, it created a sense of normalcy and control that one does not always achieve when you have epilepsy. Andrew noted that he needed to exercise not only for his physical health, but for his mental health as well. This was shown within this year as his psychological ups and downs were linked to exercise and seizure activity. This last narrative seemed to show a personal growth in regards to Andrew's attitude to his epilepsy. He understands he has limits, yet also understands that he can work within those physical limits. By ignoring his epilepsy status, it did not help him keep an exercise routine, it hindered him.

12.6 Concluding thoughts

I was intrigued by Andrew's narrative. Showing so many changes over time, it was exciting to show another view of the roller coaster narrative. Each trough differed slightly and there were varying factors that caused the peak and repeated trough (e.g., medication side effects, social support, seizure frequency, etc.). Essentially though, he did not seem to go backwards (i.e., overall he did not, but he did in interim periods) and learned from previous experiences. Differing from Rose's roller coaster story, he had definite peaks and troughs, not becoming cyclical within the structure, as was seen

within Rose's story. The key component to Andrew's narrative was his social support network. From a team of rowers that support as well as judge/fear him, to his doctor that gave harmful and then supportive advice, and finally to his family and friends who support and encourage his exercise habits, this network helped create peaks or troughs within his roller coaster with exercise.

Two themes that also ran through Andrew's narrative were that of stigma and acceptance. Andrew seemed to face more stigma in his sporting choices than the other participants. Perhaps it was a male-based community that increased this stigma, or maybe it was just the characters involved. This cannot be answered within this research. However, this did seem to psychologically affect Andrew's exercise life. Stating this, however, over time Andrew became more accepting of his epilepsy. Trying to lessen the stigma, he would discuss it with others and eventually took part in epilepsy community events. This was quite a sudden change over the year and it would be interesting to see if this is similar in other cases. Within his sporting life, this acceptance allowed him to maintain his exercise habits and benefit from a healthy exercise routine.

Lastly, it was important to draw attention to the difficulties with having multiple identities. Andrew seemed to have competing identities: hidden disorder and athletic identity. One impacted the other and caused a heightened emotional response when exercise was halted or increased. As he had constant changes over time, it seemed that one year was not enough to track a SWE's experiences. Documenting such changes can help medical professionals and SWE make healthy decisions regarding their exercise advice and habits.

13.0 Discussion

These narratives have communicated never-before-expressed insight into the continuous endeavour, frustrations, and successes of exercising with epilepsy as told by SWE over the course of one year of their lives. Reviewing the aims of this research, this thesis aimed to: first, present the narrative type(s) of the SWE; second, investigate the common and unseen topics within current epilepsy and exercise literature; and finally, provide stories for SWE and their social support network to use as insight into an unseen topic. In fulfilling these aims, these narratives have made a substantial contribution to literature through: 1) the introduction of narrative types for the SWE; 2) the first documentation of time's effect upon exercising with epilepsy; 3) the positive and negative psychological and physical effect of exercise for the SWE; 4) identity's (athletic and epilepsy) effect on coping with their epilepsy and exercise routine; 5) the influence of social support (e.g., doctors, family, friends, etc.) on SWE's QOL and exercise routine; 6) the effect of sport choice upon health status for the SWE; and last, 7) through the use of narrative analysis, represented the individual experience of a SWE, showcasing for the first time within research the uniqueness of the SWE's exercise experience. Examining these findings more closely, this chapter will connect these results to current literature, and discuss how the new findings significantly contribute to research literature in exercising with epilepsy. First, the narrative types found will be addressed in their relationship across the participants and their link to current literature. Next, thematic connections within sport/illness and health literature will be discussed, whilst finally, researcher reflection on the narrative process and completion of this research will be presented.

13.1 Narrative type of the SWE

Using Frank (1995) and Lieblich et al. (1998) as a guide, the resultant themes that were pertinent in each holistic story were examined, and using my overall judgement on how each participant relayed their experience through the interview and analysis process, presented the narrative type of each participant. Firstly, Frank's (1995) narrative types were examined for relevance amongst the participants. Although there were elements of 'fit' within some participants in regards to Frank's work, none seemed to accurately portray the holistic story of the participants. Instead, there seemed to be elements of each narrative type within one narrative over the year. For example, Andrew's peaks and troughs coincided with restitution and chaos narrative types (Frank, 1995). Believing that one day he will be cured, or on a constant search for a cure, he portrayed a restitution that "yesterday I was healthy, today I'm sick, but tomorrow I'll be healthy again" (Frank, 1995, p.77). This seemed to be shown within the first, third, and fourth narratives. However, within the second narrative, and in elements of the fourth, there was shown a chaotic storyline as the elements of fear and restriction were introduced into the narrative. Trying to decide how best to depict such a story, I began to realise that epilepsy was not the same as other disorders/illnesses. Epilepsy differs as it is unpredictable. As seen through these narratives, even when a SWE has been seizure-free for a year, there is an element of fear or the knowledge that he/she has to daily consider seizure triggers (e.g., tiredness, blood sugar levels, hormone levels, etc.) or else 'it' will come back. As seizure frequency was not as common for Andrew as it was for Gwen and Maya, and because his sporting life changed drastically over the year, it

seemed that this may have heightened his emotional reaction to portray elements of chaos.

For Gwen and Maya, this fear or knowledge of being ‘sick’ was constant as seizures were continuous. They had the highest seizure frequency, yet differed as how best to cope. Although Gwen portrayed elements of chaotic narrative in her intense frustration to achieve a regular exercise routine, she did not give up on this goal. As a result, it did not seem that chaos fitted Gwen’s story. As her narratives did not fit within the restitution or chaos narrative type, nevertheless, it did seem that Gwen expressed elements of a quest narrative. At the end of the year’s process, I saw a slight change within Gwen of acceptance and adaptation. Although this was not a heightened epiphany (Frank, 1995), it seemed she had started to come to terms with the daily battle that is exercising with epilepsy. This was shown in her adaptation and growing acknowledgement that she needs to listen to her body and not always ‘push’ it as much. For Maya, there did not seem to be any elements of a narrative type as was found within Frank (1995). Her consistent feelings of hypochondria and denial had not produced an epiphany nor greater acceptance over the year.

For Rose, initially, her story depicted a restitution narrative. Having long periods of time seizure-free, she seemed to believe that she could be ‘normal’ and that her seizures did not affect her exercise life too dramatically. However, this seemed to change over the year with an increased seizure frequency. It did not seem that Rose fell into a chaotic storyline as seen in Andrew. Instead, although she had initial moments of negative emotions, by the year’s end, she began to imbue the sense of a quest narrative. She seemed more comfortable in her identity as a SWE and not as fearful to let others

know. This may have been the result of more seizures, hence she felt as if she was a SWE. However, it did also seem that discussing such issues with me over the year had created a greater sense of self-reflection that is shown within a quest narrative (Frank, 1995). As Frank's narratives did not prove to be a consistent fit for the SWE, I examined Lieblich et. al's (1998) structures as well as observed new story types that developed.

Using Lieblich et al. (1998) as a guide, it seemed most of the narrative types within each narrative could be found within this literature. Firstly, the steady narrative was seen within Maya's year documentation. Maya's constant denial and lack of acknowledgement of how her exercise routine was affected by epilepsy showed through as a steady narrative. Maya contradicted herself in saying her swimming benefited her epilepsy, yet often showed more seizures with swimming. I chose to acknowledge her story as more of a steady narrative rather than another type, the narrative of progress, as there were not constant benefits of her exercise on her epilepsy. For her mental health, confidence, and self-esteem, however, this differed. Increased exercise consistency did create a narrative of progress for Maya, as she seemed more content and happy within herself when she exercised more. However, it seemed fitting that in connection with seizure frequency, exercise, and the psychological effects this had upon Maya, her story will be shown as steady. Viewing her story as steady, Maya's narrative is being portrayed as more of a balance between frequency of seizures and exercise, rather than having mostly positive or negative effects.

Andrew's narrative had similarity to the narrative shown within Lieblich et al. (1998) as trial and error. Although Andrew's narrative was similar in structure, I felt that naming it roller coaster was more fitting to Andrew's story, compared to a title that

conveyed he was trialling new adaptations and not succeeding. His ups and downs were similar to the experience of riding a roller coaster, as within every interview, I felt like I was experiencing his emotional journey and it was up and down, not smooth sailing.

Rose, experiencing multiple forms of narrative structure, showed the roller coaster to be fitting to her narrative form as well. Describing her narrative as a roller coaster takes into account the progressive, trial and error, and cyclical nature of her narrative. For Rose, her story began as a progressive narrative. Benefits were seen with more exercise, not less. This however, turned cyclical at the time of the third interview. Her ups and downs, and 'loop-to-loops' (i.e., vicious cycle) caused a feeling of a constantly changing roller coaster where exercise was both beneficial and a hindrance. As Lieblich et al. (1998) do not have a cyclical narrative structure, this will contribute to illness and exercise literature.

The vicious cycle (discussed in the next section) was Gwen's clearest narrative form, and evident throughout her year's documentation. Gwen physically would see an increase in seizures with more pressure on her body, thus causing the cycle of frustration and worry. Connecting to Lieblich et al.'s narrative forms, Gwen could also be shown to have a 'narrative of decline.' This was shown as an increase in exercise was usually seen as more detrimental to her health, thus presenting the negative formation of the narrative. However, there were benefits as well, as was seen in the positive psychosocial effects (e.g., self-esteem, confidence, control of her body), thus creating a varied narrative type.

For all the participants, the relationship between exercise intensity and frequency, seizure frequency, and psychosocial benefits/drawbacks appeared to correspond over time, showing that the SWE's story is more complex than previously shown. For example, examining the concepts of exercise frequency and seizure frequency, there is a conflict of "the more exercise I do the healthier I feel," compared to "the more exercise I do, the more seizures occur." Although not the same result for each participant, these narratives reveal that it is not as much exercise frequency that affects seizure frequency, but more exercise intensity. This was also found within research, as intensity creates a heightened seizure occurrence (Arida, Scorza, Terra et al., 2009; Eriksen et al., 2002; Nakken, 1999; Nakken et al., 1990; Sirven, 2009; Steinhoff et al., 1999).

This research presented the multiple narrative types that represented the SWE's exercise experiences. It seemed as though the ongoing and ever-changing nature of epilepsy does not fit one storyline, but multiple. This has not been acknowledged yet within current literature and would be of interest to continue investigating in the future. Adding a new narrative of the vicious cycle was an exciting addition to narrative literature and would benefit from further research. Next, the vicious cycle narrative will be described.

13.1.1 Vicious Cycle

Vicious cycle was a new narrative type that emerged from these narratives. This was exhibited through the cyclical nature of the psychological and physical effect of seizures and exercise. The cycle was presented as: a) desire to exercise; b) exercise; c)

seizure and prevention of exercise; d) frustration and anger/desire to exercise; e) overcompensate with intensive exercise; and starting the cycle again, f) seizure. Medical professionals discuss the importance of exercise (Ablah et al., 2009; Elliott, Jacobson, & Seals, 2006), an importance mirrored by the participants' experiences, yet the vicious cycle occurs when they cannot exercise because of their seizures. When does the cycle end? How will it end? Unfortunately, this was not a narrative type that seemed to have a clear end. It was an ongoing story of trying to find a successful method of exercising with seizures. However, as shown in Gwen and Rose's narrative, one way to 'end' or change the cycle is to adapt the exercise routine. This created a momentary linear progression, compared to an ever-ending cycle. Although the change in shape was not constant, and with increased frustration reverted back to cyclical form, it did show that adaptation and acceptance of bodily limits may be the beginning of coping with the vicious cycle and eventually evolving it into a linear narrative. Although the vicious cycle was shown within Gwen and Rose's narratives, it has yet to be exhibited within current literature prior to this research.

Having reviewed the narrative types or hows found within this research, next the whats or thematic results will be presented to show relevance within current literature as well as new additions to the scientific and SWE community.

13.2 Temporal variable

Through the discussion of epilepsy over time, "the narrative transforms symptoms and events into a meaningful whole, thereby creating the world of illness" (Hyden, 1997, p.56). Using three to four month intervals between interviews over the

course of the year, changes in thematic structure and storied expression were found over time. This temporal effect upon the SWE has yet to be found within current literature. The ongoing and constant changes in, for example; self-confidence, emotional happiness, physical fitness, exercise routine, social support, etc., have now been documented as having a strong impact upon the psychosocial experience for the SWE. These narratives have shown that it is of high importance to the world of epilepsy, sport, and health that the effect of time is accounted for in regards to the psychological and physical health of the SWE. The structuring of the narratives via the interview timescale was aimed at providing the view of the temporal effect on the exercise experiences for the SWE. Time's affect on the thematic evolution was shown to be an influential factor to the formation of each narrative and each participant's overall story.

As a chronic illness, epilepsy does not seem to fit the typical illness story. However, in discussions with participants, there was a sense of before epilepsy, during, and future. In other words: before diagnosis, living/exercising with chronic seizures, perceptions of future living/exercising with chronic seizures, and seizure control. This was a timescale that shaped the epilepsy and athletic identity of the participants. For example, Rose discussed life before seizures and how it had changed post-diagnosis. Within the first interview, there was a lot of discussion on "who I was" and "what I did", and the shift to "who I have become." Similar findings are found within the illness literature (Charon, 2006; Frank, 1995; Hyden, 1997; Jacoby & Baker, 2008), and can also be linked to the identity concept (discussed further below). Rose's emotional response shifted over time as a result of the variable of seizure frequency. Gwen had similar statements of identity crisis as Rose, however, as she has had epilepsy for most

of her life, it did not come across as strong. For Gwen, a shift in emotional response was seen when changing sports (discussed later in this chapter), however she still struggled with the emotional reactions of frustration in her inability to sustain an exercise routine. Andrew had the most change out of the participants. Seeming to change every 3 months, this showed time was a strong factor in his exercise experience and identity (to be discussed in next section). His experiences were marked by outside variables causing this change (e.g., medications, seizure frequency, doctor advice, etc.), and this increased in variance over time. Maya, on the other hand, had the least amount of change over time. Maintaining consistent in her athletic identity, seizure frequency, sport type, social support, and medication, Maya showed steadiness over time. Overall, it appeared that Maya and Gwen had the least amount of change over the year. There was no set explanation for the lack of a major shift, however, I believe outside variables played a part. Common variables that could explain this are; that neither of them had medication changes within the year; they both have partial seizures (one complex and one simple); and both have had epilepsy for most of their lives. These could be elements to what caused the consistency over time, or another unknown variable may be the cause.

For the participants, the ability to cope with uncontrolled seizures proved to be ongoing, and although some had been diagnosed for at least 20 years, this was still a daily battle to successfully exercise with their seizures. This intrigued me. Why does it not get any easier to exercise with chronic seizures? Is it a constant process that multiple variables effect? I believe it is. From these stories, as the participants worried about whether to exercise or not to exercise, whether or not there was a link of exercise to their seizures, and whether their well-being benefited to keep exercising, it appeared that time

did not always make it easier in regards to successfully exercising with epilepsy. Acceptance and adaptation was ongoing, and by the end of the year for each participant, I came away thinking their story had not ended. These ups and downs may continue or there may be stagnation. Seizure frequency was a key variable in creating the constant changes. This was shown, as even over the span of a year, the decision to exercise was a constant, often daily, process. As a result, it seemed that only with controlled seizures, will a heightened sense of security whilst exercising be created. As time and identity were closely linked, the next section examines the effect identity had on their exercise routine and emotional response to exercise or lack thereof.

13.3 SWE and identity

Using the theoretical foundations of symbolic interactionism, identity was examined over time. In this research, I wanted to explore not only athletic identity and how it was maintained or lost as a result of their epilepsy, but also their epilepsy identity and feelings towards being labelled as disabled. Does their epilepsy define them? Do they feel that they are disabled? Does this label affect the way they define themselves within their sporting life? The following will examine athletic identity, hidden disorder (epilepsy identity), and disabled identity, linking the findings to current literature.

13.3.1 Athletic identity

For each participant, athletic identity was affected over time. Supporting the ideals of symbolic interactionism, this research showed how outside social and personal variables impacted the SWE's identity. Depending on the strength of their athletic identity and interacting outside variables, their emotional response varied over the year.

Such variables included: sport/exercise importance, sport choice, seizure frequency, medication effects, exercise routine, social support networks, the stigmatized views of others, and time. Some of these variables have shown a similar effect to identity (e.g. social support, sport/exercise importance, sport choice, and time), within health, injury, and exercise literature (Allen-Collinson & Hockey, 2007; Anderson, 2004; Charmaz, 1983; Charmaz, 1994; Dickson et al., 2008; Donnelly & Young, 1988; Hockey, 2005; Houle, Brewer, & Kluck, 2010; Irvine et al., 2009; Lavalley, Gordon, & Grove, 1997; Phoenix & Sparkes, 2007; Sparkes & Smith, 2002; Stevenson, 2002; Weiss, 2001; Ylvisaker, McPherson, Kayes, & Pellett, 2008). However, these connections have not yet been introduced to the epilepsy research community, nor has their connections been explored regarding SWE. Interested in exploring the concept of the generalized other, these narratives portrayed that for SWE, the level of athletic and/or disabled identity was affected depending on not only how their social sporting group/team perceived them, but also their own self-perception of bodily limits/ disability. This will be further discussed below. The following will describe how each participant's athletic identity affected their emotional response in regards to exercise interruption.

Andrew provided a strong example of the effect of an athletic identity on the emotional response of an interrupted exercise routine because of epilepsy. Beginning the year as a rower, after experiencing multiple seizures and losing his sport routine, he then felt alienated from the identity of 'an athlete.' Andrew's former self-image was crumbling away, causing him to lose his self, which corresponded to similar findings in Charmaz (1983). However, as seen in those with other chronic illnesses, acceptance and life adjustment caused the regaining of a former self (Dickson et al., 2008). The effect

his team had upon his self-perception seemed to negatively affect his athletic identity. It appeared that the more he was portrayed to be ‘different’ from his social group, the more he began to see himself in this way. Although this changed over time, his end narrative did not portray the same “rower” as before. It seemed that the less he was part of the social sporting group, the less he felt he belonged.

Gwen’s heightened emotional response to a loss or prevention of exercise showcased her strong attachment to an athletic identity. Describing herself as a “sprinter” and “sporty” whilst younger, it seemed being diagnosed with epilepsy had caused a shift in her exercise routine, yet not in how she identified herself (Rhodes, Nocon et al., 2008; Stevenson, 2002). This was interesting to note as it had been more than 20 years since she was a track sprinter, yet this identity had remained with her. One reason for this reaction could be the invisibility of epilepsy. Unlike physical disability, her limits do not appear on a daily basis, thus affecting her identity (Charmaz, 1983; Charmaz, 1995; Rhodes, Nocon et al., 2008; Smith & Sparkes, 2008b; Sparkes & Smith, 2002). Comparing her identity reaction to those with new physical disabilities that affect athletic identity, Gwen’s attachment to her identity presented a significant contribution of knowledge into invisible disorders and athletic identity. Like Andrew, her athletic identity added to her frustrations and anger at her lack of exercise routine. Gwen’s social support did not seem to affect how she viewed her athletic identity, it seemed to present her limitations more, leading to a heightened sense of difference and/or disability. This label was fought over the year, and will be discussed further within this chapter.

Rose, being the most recreational of the participants, did not portray a strong sense of identity linked to her sport. Exercise was important for her to keep fit, but if it

would cause seizures, she would not exercise. Although Rose viewed exercise as important to her general health, I did not gain a sense of strong athletic identity definition as I did with the other participants. This decision to not exercise if feeling “seizurey,” was shown in other research where athletic identity was not as strong (Son, Kerstetter, & Mowen, 2009). In regards to a social network’s affect on Rose’s identity, it seemed to not have as much of an effect on her athletic identity. Instead, it seemed her disabled identity was heightened through others (see 13.3 below)

Becoming slightly more accepting of physical limits over time, Rose, Gwen, and Andrew seemed to realise that their exercise was affected and that continuing as though they were seizure-free was not the safest option. Andrew and Gwen seemed to struggle quite frequently with the desire to maintain sporting habits and identity. Feeling like they had no control over their bodies led to frustration, and in Andrew’s case, symptoms associated with a depressive state. It seemed a loss of athletic identity created the negative emotional effect already commonly seen in injury, chronic illness, and ageing literature (Allen-Collinson & Hockey, 2007; Hockey, 2005; Lavalley et al., 1997; Phoenix & Sparkes, 2007; Son et al. 2009; Sparkes & Smith, 2002). Andrew’s refrain from exercise out of fear, conflicted findings in research, which would have shown a person with a strong athletic identity to continue to exercise, rather than stop as Andrew had (Allen-Collinson & Hockey, 2007; Murphy et al., 1996; Stevenson, 2002; Weiss, 2001). However, his strong sport attachment was shown through his emotional reaction to the loss of exercise which was heightened because of his athletic identity.

Maya differed to the other participants as it seemed her sporting goal and identity were stronger than her acceptance of personal limitations or even safety. Sturm

et al.'s (2002) case study showed similar results of a SWE's refusal to accept limitations or doctor's advice for a participant with ongoing seizures and heightened sport identity. Maya's narratives portrayed results of the denial of bodily limitations as a result of a strong athletic identity. Like Rose, Maya's identity creation/stability did not seem to be affected by how others viewed her. This was shown through her constant dismissal of others' opinions on her sporting life.

Comparing these results to identity within injury and illness research, epilepsy has shown similarities to that found within current literature (Allen-Collinson & Hockey, 2007; Borkoles et al., 2008; Graham et al., 2008; Hockey, 2005; Phoenix & Sparkes, 2007). However, not being the clear end to any exercise or sporting habits, epilepsy created more of an ongoing cycle of discovering how best to exercise, therefore aiming to maintain identity. The emotional impact was similar to career-ending injury (i.e., depression, frustration, identity confusion, etc.) (Kleiber & Brock, 1992; Podlog & Eklund, 2005; Smith & Sparkes, 2008b), yet also differed in that it was not career-ending for these participants. Andrew could still return to rowing, Rose could still go for runs, Maya could still swim, and Gwen could still go to the gym. However, on any given day, a seizure could occur and the cycle of emotional response would continue. Exploring this topic, the cyclical effect presents a heightened emotional response that causes ongoing identity confusion as well as similar emotional responses to injury. However, injury research shows a tapering off of symptoms over time (Evans & Hardy, 1999, as cited in Pargman, 1999). These results show that for SWE, this may not occur because they have yet to accept their ongoing disorder. Seizures come and go; it is not an ongoing physical injury. Some days SWE seem normal, while the next, they can feel

disabled. Similar identity effects were seen within current multiple sclerosis research within sport (Borkoles et al., 2008), however, epilepsy's cyclical emotional effect on athletic identity has not yet been shown within current literature. One question that kept returning was whether there was a higher impact to one's athletic identity if one cannot exercise consistently, as seen in these SWE? It seemed as though the uncontrollable force of seizure frequency and resultant reduced exercise habits, created a more intense emotional reaction to the lack of exercise.

13.3.2 Hidden disorder

Personal reflection: *I believe that epilepsy differs because of its ability to only become visible at certain times. It is as if you do have some power over making it visible. The participants knew their triggers, and if they were in danger of exposing their ill body, more often than not they would avoid that trigger. At times, it could not be prevented, thus increasing their feelings of negativity to their ill body. Outside variables allow it to go one way or another. This makes for a diverse topic, where it would not be the same for every SWE, yet as seen by these participants, it seems apparent and important to present.*

The following section will address the topic of hidden disorder and how it affected the participants' athletic identity. Being a hidden disorder, epilepsy differed from research investigating other visible disorders/illnesses such as multiple sclerosis or Parkinson's disease (Borkoles et al., 2008; Graham et al., 2008; Kasser, 2009). The hidden aspect of epilepsy seemed to increase the participants' willingness to push themselves to exercise when they may have not physically been able to or should. Also,

it created a false sense of security to exercise without others, to not feel physically limited, and helped maintain their athletic identity.

Examining each participant, I felt that the further hidden they were, the less accepting they were of their limitations. This increased hidden aspect of their identity seemed to also correspond with feelings of felt stigma. Initially, Rose seemed to hide her epilepsy as only close friends and family knew. She did not like telling others and during her interviews, her physical reaction (head down, flushed face, embarrassed giggle) whilst discussing this showed that she was embarrassed as well. Within exercise life, she kept it hidden until she had to tell others. Upon having a seizure whilst running, Rose was awoken to the potential dangers to herself by remaining hidden. Similar in mindset, Andrew and Gwen both felt that remaining hidden benefited those around them as well as themselves. Whether it was in the boat, at the gym, or even in the swimming pool, they expressed that since they were not visually ill, they felt more secure to exercise and did not feel the need to disclose information to others. As embarrassment was the common result of disclosure, this also created a stigmatic effect, as seen in situations expressed by Andrew. In maintaining a hidden identity, Gwen and Andrew expressed that this allowed them to be 'normal' for the time being, and it allowed them to feel healthy and in control of their body. It also allowed them to not feel limited as epilepsy seemed to limit their exercise routine. This personal benefit to maintaining a hidden identity also compared similarly to Maya's non-disclosure in every swimming event she participated in.

Differing in the decision to disclose her epilepsy, Maya did not seem to struggle telling the non-exercise world about her epilepsy. However, like the other participants,

she did not discuss it as often within an exercise environment. This was seen in her failing to always disclose her epilepsy with the proper authorities in some swimming events for fear of being withheld from exercise. This aspect of her epilepsy identity was quite interesting to me. It seemed she realised that there were consequences to having this disorder, and although she felt she should not stay hidden, hiding provided more benefits within the sporting world.

The psychosocial impact of a hidden disorder upon their exercise routine seemed to be both positive and negative. On the one hand, each participant described feeling free and ‘normal’ for the time whilst exercising. Exercise seemed to be a positive time for them; a time where they could escape their feeling of being ‘ill.’ Although this was a positive aspect of having a hidden disorder, on the other hand, safety concerns came into play. Not telling lifeguards or officials, they were playing with their health as well as their lives. Not disclosing their illness did not only have an effect on them, but it affected their social network as well. This was seen by worried friends or family and even medical professionals stressing the importance of disclosure. Often such advice was disregarded for that glimpsed feeling of ‘normalcy.’

Exploring the topic of discrediting (Charmaz, 1983), it was desired to see if similar results could be shown for the SWE. Charmaz states, “many suffer from discreditation related to their decreased and now marginal participation of the normal world” (1983, p. 181). Examining such thoughts for SWE, this feeling of being discredited may be the result of feelings of stigma and social exclusion because of their epilepsy. Being looked down upon, people being afraid once you disclose your epilepsy, being told to exercise only in your room, such events created feelings of (un)normalcy

for the participants. It caused the participants to feel less normal and as a result was a cause of their desire to remain hidden.

Hidden disorder was part of their epilepsy identity. Listening to them discuss how they felt different and the benefits versus downfalls of having epilepsy, each seemed to portray that epilepsy was a hidden disorder and within the exercise world, they prefer to stay hidden. Although each recognised the importance of epilepsy being de-stigmatized, i.e., the reduction of stigma through discussing their epilepsy with others in the sporting world, none of them really felt that in the short term this would help. However, Andrew and Rose became less hidden as time went on. I felt they began to embrace their epilepsy identity and had discovered the pitfalls of staying hidden. This was shown through the participation of activities with Epilepsy Action UK, to discussing epilepsy with family and friends. They began to get people to recognise their epilepsy and see that they were the same person, who had moments of physical lapses. Although hidden disorder was a theme marked through each of the participant's identities, being labelled with the term disabled was seen as not an accurate label and even offensive.

13.3.3 Disabled Identity

The topic of disabled identity has an abundance of research on its stigmatized effect and psychosocial consequences (Charmaz, 1994; De Wolfe, 2002; Galvin, 2005; Irvine et al., 2009; Smith & Sparkes, 2008b; Watson, 2002). Investigating the topic of disabled identity with the participants, there was an overwhelming sense of “that is not me.” Each participant seemed to have the stereotypical viewpoint of disability. For

example, Andrew remarked, “I see disabled as the stuff my sister has... She’s in a wheelchair, 24 hours a day.” This is not an uncommon opinion of what classifies as disabled, as seen through Watson (2002). The lack of acknowledgement of being disabled decreased the felt stigmatization for the participants. It seemed the more they kept hidden and did not acknowledge their epilepsy as a disability in public life, then it was not a disability in their sporting life. In other words, they would not need help, nor would they need to be hindered from doing their exercise. Ironically, when discussing disability benefits, such as a bus pass and monetary benefits, participants were eager to use their epilepsy to their advantage. This was interesting to note as it seems that they use their disabled identity to their pleasing and their benefit. The only exception was Maya, who as previously stated, feared the effect this would have upon her acceptance to compete in open water competitions.

Personal reflection: *When discussing such topics with the participants, I had to agree that these were my same feelings. I have a bus pass, get discount on travel, even look for special discounts where I can show I am disabled. As time has gone on, I have accepted my disabled identity outside sport and a lot has come from listening and talking to these participants. However, within sport, I remain ‘non-disabled.’ How will this change? Does it have to?*

Perusing previous literature on hidden disorder and disabled identity within epilepsy and exercise, I was left wanting. There is an absence of literature investigating such a relationship. Within exercise and sport, it would be of interest to further examine correlations between hidden disorder and disabled identity. What makes a person stay hidden? Do these narrative findings evoke similar feelings in other SWE? Findings such

as the ones discussed here are surely not the sole themes within a hidden disorder and disabled identity. It is of interest to progress this research further through examining hidden disorder and disabled identity within different sporting environments, e.g., team versus individual sports, genders, as well as across different seizure severity (i.e., uncontrolled versus controlled) and type.

Following the discussion on identity, the topic of ‘the body’ is of particular interest to discuss. As seen in illness and injury literature, (Charmaz, 1995; Dickson et al., 2008; Frank, 1995; Smith & Sparkes, 2008b; Sparkes, 1999), the ill body and sporting body have an abundance of research investigating this topic. The following examines how the concept of ‘the body’ was portrayed through the participants’ narratives.

13.4 The ill versus healthy body

Exploring the ill versus healthy body (Corbin, 2003), these narratives have shown that exercise has a beneficial effect on how a SWE views their body. Commonly seen within PWE is a feeling of a loss of control of their body (Raty & Larsson, 2011). This was confirmed for the SWE, as each participant portrayed such a feeling through these narratives. Whether it was Gwen’s feeling that her body dictates to her, rather than her dictate to it, or Rose discussing the need to do certain measures to keep seizure-free, the participants expressed similar findings regarding body awareness with a disorder/illness (Allen-Collinson & Hockey, 2007; Charmaz, 1983; Charmaz, 1995; Corbin, 2003; Sparkes & Smith, 2002).

As the participants felt more comfortable with a hidden ill body than allowing epilepsy to become visible, there seemed to be a resultant struggle or fight with their own body, which caused frustration, anger, and depressive symptoms in the participants. The motivation to maintain their identity by examining the physical body was similar to research within injuries and sport (Allen-Collinson & Hockey, 2007). Describing that their body seemed to look healthy (e.g., physically fit), caused them to feel healthier. However, there seemed to be another side to this. When a seizure did occur, each participant resorted to the perception of their body as ill; resulting in a negative emotional response. It seemed that confidence, faked or real, and not desiring their epilepsy to be all encompassing, added to this image of a healthy versus ill body. They expressed motivation to maintain a normal exercise routine, preserving the image of a healthy body on the forefront of each participant's mind. It seemed that only the eruption of a seizure disturbed this. Only in the case of Maya were these eruptions not disturbing to sporting life (e.g., seizure during swimming). Examining these results and linking them to current literature, it seemed that there are similarities and differences with injury and other illnesses within sport research. Differences were shown as, compared to an injury or illness (Allen-Collinson & Hockey, 2007; Borkoles et al., 2008; Charmaz, 1995; Smith & Sparkes, 2008b), epilepsy was not as physically constant. In other words, although seizures were occurring, there were days, weeks, even months where the participants would be seizure-free. This feeling of a lack of consistency in an ill body created a variety of emotional reactions, thus generating an up and down emotional response. These reactions to their epilepsy and sporting body led to the issue of struggling *with* or *against* their disorder (Charmaz, 1995).

Shown to struggle against and with their epilepsy, these SWE often described that their body was seen as an enemy, holding them back from exercise and living a healthy life. This was particularly shown within Gwen and Maya's narratives, as they constantly struggled against their illness. Although Gwen exhibited elements of struggling with, her holistic story portrayed a constant battle, moving between with and against. Maya seemed to struggle against her epilepsy, portraying elements of anger that she could be prevented of accomplishing her exercise goals because of this disorder. Their anger and frustration, or ignoring of symptoms seemed to present such sentiments. As stated in Charmaz (1995), "they view their illness as the enemy with whom one must battle" (p.663). For Andrew and Rose, I got a sense that over time, they had learned to struggle with their illness, rather than against. By the end of the year, there was more acceptance as well as willingness to recognise a weak body, resulting in adaptation of an exercise routine. It seemed for them, this would allow a more successful exercise life and lead to a healthier body (Charmaz, 1995).

Personal reflection: *It felt comforting that someone else thought that it was not fair as well. It felt comforting that there was a strong sense of frustration caused by the confliction between the body's ability and our mind's desire. This comfort does not make my body healthier, but I do think it allows me, a SWE, to see that my emotional reactions are not out of the ordinary and although I may have epilepsy, I can exercise and lead a healthy life.*

Although these narratives showed a fight with the individual's body, one theme that came across was the benefit of exercise upon their view of their body's healthy status. It was portrayed that through exercise, the participants felt they had more control

over their body, thus enhancing their self-perception of a healthier body. Similar feelings are found within research investigating exercise and chronic disorders (Graham et al., 2008; Kasser, 2009). Unlike sentiments found within research for people exercising with multiple sclerosis (Borkoles et al., 2008), exercise did not always make the participants feel more ill, it seemed to increase the state of normalcy. For example, Gwen describing her time swimming as, “I feel more in control, I feel more relaxed.” For the participants, many reported a feeling of relaxation and stress relief as a result of exercise. For example, helping them feel guaranteed to sleep, thus reducing the risk for seizures. However, these positive sentiments of the benefits of exercise also created strong negative reactions of frustration, anger, or depression when exercise was ‘taken away’ or prevented by the occurrence of seizures. An example is seen in Andrew and his feelings of anger and inadequacy at only doing weights in his room. This state of healthy versus ill body and exercise’s effect upon the SWE’s view of their body should be examined further within future research. Embedded throughout each narrative, the topic of stigma was connected to the personal and social image of health versus ill body and identity. Next, discussion on the psychosocial effect of stigma on the SWE will be examined.

13.5 Stigma

The topic of stigma was prevalent within each narrative of the participants. Confirming similar results found within research (Elliott et al., 2006; Goffman, 1963; Jacoby et al., 2004; Jacoby, 2002; Troster, 1997; 1998), it seemed the stigmatic effect of living with epilepsy interfered with their exercise life. Although it was evident that stigma affected disclosure of their epilepsy within their exercise life (e.g., sports

officials, team-mates, lifeguards, etc.), it also added to their anger or frustration concerning exercising with epilepsy.

For each of the participants, the effect of stigma upon their exercise life varied. For example, Andrew's initial resilience to disclose his epilepsy with his teammates or coach resulted in a few teammates becoming unfriendly and elements of enacted stigma (Scambler & Hopkins, 1986) once his epilepsy was revealed. This negative result of disclosure caused stigma to be an important concept within Andrew's story. Examples within research of such drawbacks to disclosure are seen within everyday life for PWE (Goffman, 1963; Jacoby, 2002; Jacoby et al., 2004; Scambler & Hopkins, 1986; Troster, 1997; 1998); however, it has not been explored within a sporting context. This has provided an initial glimpse into possible issues that have arisen for SWE.

Varying scenes of stigmatic effect occurred within the other participants. One example of notable felt stigma was Maya's decision to keep her epilepsy from officials in races. For Maya, this seemed the most successful way to get approved to swim. This decision caused me to realise that Maya was aware that epilepsy has this stigma attached, particularly in regards to swimming. Although she claimed she did not care, by acting in such a way, I felt that these were not her true feelings. It became apparent that she felt it more beneficial to stay hidden, thus decreasing the resultant stigma that may occur as a result of disclosing her epilepsy to swimming officials.

Personal reflection: *Her behaviour in regards to this nature made me squirm. However, I knew that I may have done the same if I was in the same situation. No one wants their*

epilepsy to hold them back, and because others do not know that SWE can exercise safely, then maybe it is best to stay quiet.

Rose had some experiences with enacted stigma as she expressed anger and/or annoyance at jokes made by family and friends at her expense. It seemed mainly stemming from the lack of others' education of what epilepsy is, yet this did affect Rose and caused her to express felt stigma in other situations. Although Gwen and Rose had similar felt stigma concerns within their narratives (e.g., not telling lifeguards, friends, gym staff, etc.), there was not as strong an affect on their exercise life as it was for Andrew and Maya. This may have been because Andrew and Maya were more competitive with their sport, thus their epilepsy could have a different social impact. To progress this research forward, it would be of interest to examine the others' (e.g., friends, family, sports coaches, teammates, etc.) point of view regarding exercise. Exploration could continue through the use of qualitative methods to investigate the stigmatic effect of epilepsy and whether this is strong because it is felt stigma, with the SWE 'knowing' how others view their epilepsy, or enacted stigma, as it is confirmed by others' view.

Stigma was positively linked to a change/reduction over time. Although Gwen and Maya did not exhibit a change in felt stigma, both Andrew and Rose seemed to be more open about their epilepsy as time went on. As Andrew became more comfortable within his own identity as a SWE, it seemed that he did not feel the enacted stigma nor felt stigma in regards to new acquaintances. Also becoming more comfortable with her identity as a SWE, Rose's increased openness to friends was caused by her social support network reaching out, rebutting the stigma that she perceived. This seemed to be

another topic of interest to explore into why the other factors might have caused this slight shift, yet not with Gwen and Maya. As was shown through the emotional reaction to the stigmatic effect of one's view of their body, the following section will provide common emotional responses from the participants as well as the keys as to how one might successfully exercise with epilepsy.

13.6 Emotional response

The emotional response to exercising with epilepsy provided unique insight that has yet to be discussed within current literature. Current research produced evidence of the psychological benefits in relation to participation in physical activity, depressive effect due to the lack of exercise, fear to exercise, and denial of medical advice (Ablah et al., 2009; Dubow & Kelly, 2003; Sirven, 2009; Sturm et al., 2002; Wong & Wirrell, 2006). However, using narrative inquiry, a more in-depth and first person insight was achieved, producing new concepts and variables (e.g., athletic identity and SWE, stigma, social support, etc.) than seen within current literature. The following will present the common emotional reactions to exercise found within these narratives.

Prior to discussing the negative sentiments concerning a lack of exercise, the psychosocial benefits to exercise will be shown. As previously touched upon within the earlier sections, exercise was seen to have a relaxing and beneficial effect for the participants; for example, confidence, higher self-esteem, higher self-efficacy, and improved mental state were seen as a result of exercising. Similar findings are seen in research on exercise and epilepsy (Conant et al., 2008; Dubow & Kelly, 2003; Eriksen et al., 2002; Lundgren, Dahl, Yardi, & Melin, 2008; Wong & Wirrell, 2006).

Participants explained that the more they exercised, the more they maintained their athletic identity, felt in control of their body, and had a relaxed mental state. Current epilepsy and exercise literature is in agreement with these findings (Arida et al., 2013; Conant et al., 2008; Eriksen et al., 2002; Heise, Buckworth, McAuley, Long, & Kirby, 2002; Sirven, 2009; Wong & Wirrell, 2006). As benefits to exercise for PWE/SWE are seen within quantitative and medico-scientific research (Arida et al., 2013; Dubow & Kelly, 2003; Nakken, 1999; Sirven, 2009), it would be of interest to explore such psychological benefits of exercise within further qualitative research in order to provide more possible responses than found within this thesis. Through each participant, although there were negative side effects from the lack of exercise, I also gained a sense of exercise adding something extra to their lives. May it be team bonding, relaxation, staying healthy, or even a sense of accomplishment of doing something that no one else has done, exercise had a positive effect. Progressing research from this thesis, providing more SWE views of positive responses from exercise may allow medical professionals to actively encourage exercise and SWE to become more eager to participate. As the positives of exercise have been revealed, next the negative emotional responses will be presented.

Physical exercise had such an impact for the SWE, that the reduction or elimination of physical activity produced dire psychosocial circumstances (Dubow & Kelly, 2003; Eriksen et al., 2002; Nakken, 1999; Sturm et al., 2002; Wong & Wirrell, 2006). Exhibited within Andrew's second narrative, halting his exercise created depression symptoms, lack of confidence and self-worth, and social reclusion. Although exercise maintenance was desired, fear, manifesting itself in diverse ways, was prevalent

as an obstruction for the participants in their exercise lives. For example, Rose's fear of seizures had multiple factors. Not only was she concerned for her safety, but also the possible loss of her driver's license and subsequent increased medication levels. Seizures meant a loss of independence as well as increased medication side effects. The participants' experiences of fear as a deterrent to exercise are in accordance with current research (Ablah et al., 2009; Eriksen et al., 1994; Nakken, 1999; Nakken et al., 1990; Sirven, 2009; Steinhoff et al., 1996; Wong & Wirrell, 2006). However, Andrew seemed to fear exercise only after doctor's orders and a public seizure. This created a domino effect, and once he was told to limit his exercise, his hesitancy increased and he was no longer brave enough to get in a boat, let alone exercise in the gym. As discussed in chapter one, Sturm et al. (2002) portrayed similar exercise advice to Andrew's doctor. Although recommendations to continue exercise for emotional benefit is prevalent in current epilepsy and exercise literature (Arida, Scorza, Terra et al., 2009; Arida et al., 2013; Dubow & Kelly, 2003; Elliott, Lu, Moore, McAuley, & Long, 2008; Heise et al., 2002; Lundgren et al. 2008; Nakken, 1999; Sirven, 2009), and was shown through recommendations to Rose and Gwen, it was interesting to witness the emotional affect of the differences in medical advice provided. As a result, examining the conflicting recommendations shown in research outputs compared to actual medical advice will need to be further explored within research.

Frustration and anger caused by prevention or lack of exercise was another key emotional response for SWE. These have not yet been exhibited within research in-depth. Frustration was common amongst all the participants as being 'held back' seemed to create a feeling of inability to control their sporting life, and to achieve valued

sporting aims. This increased frustration led to anger within the participants. Similar findings are seen within sport, injury, and illness literature (Allen-Collinson & Hockey, 2007; Borkoles et al., 2008; Eriksen et al., 2002; Kasser, 2009). Frustration from the participants was intense and exhibited their psychological and emotional connection to exercise. This frustration and/or anger only seemed to be soothed by a consistent exercise regime, and would return once it was disrupted.

Personal reflection: *I feel it is not fair that some can exercise and I cannot. I become frustrated as well when I have a week of running and then two weeks off because of seizures. However, as a result of doing this research, listening to these stories, emerging myself in these narratives, I have come to realise something I never wanted to- acceptance. Accept that my body is different, accept that some days I just cannot run, and accept that I need to be happy with that. I will not deny that I still get frustrated, I say, "It's not fair!" a bit too much. However, I no longer let it consume me. I feel that these participants will learn from this past year and hopefully other SWE will as well.*

Whether it was as an affect of Gwen's constant search for consistency, or Maya's anger at other's view of her exercise goal, feeling low or symptoms of depression was another response seen over the year. Viewing the ups and downs of Andrew's journey over the year, it felt that the lack of exercise created a deep low that his neurologist might not have known her advice would cause. Rose also expressed feeling quite down after her seizure while running. Becoming unsure of herself and not willing to risk exercise, she reported feelings of sadness that this event had occurred, putting a temporary hold on her enjoyment of exercise. Exploring this sentiment within research, similarities in emotional response (e.g., frustration, anger, sadness) were found

in injury and illness literature (Allen-Collinson, 2005; Allen-Collinson & Hockey, 2007; Borkoles et al., 2008; Smith, 1999; Smith & Sparkes, 2008b).

In dealing with these emotional reactions, acceptance and adaptation were found to ease strong negative reactions. Andrew and Rose exhibited this more so than within Gwen and Maya's narratives. Limiting exercise to certain situations or listening to their body were two of the ways adaptation kept their seizures limited and enhanced the feeling of control. Although Gwen exhibited adaptation (e.g., swimming rather than running), this change in exercise routine did not effectively ease her emotional state. She seemed to continue to want to increase her exercise intensity, which as a result, maintained her frustration levels. However, she desired to reach an equilibrium where her seizures would not dictate her exercise routine and she would benefit rather than feel frustrated from her exercise routine. Maya did not outwardly discuss adaptation to be helpful, however, glimpses of such techniques were found through limiting swimming sessions and listening to her body on days where she did not feel physically capable. This and current research encourages SWE to learn to listen to their body and exercise safely, which will allow a more consistent exercise regime (Arida et al., 2013; Dubow & Kelly, 2003; Eriksen et al., 2002; Sirven, 2009), thus leading to a reduction in negative emotional responses. Showing emotional response to be affected by multiple variables, next the topic of sport/exercise type will be discussed to explore if different exercise/sport choices could be more psychologically or physically beneficial to the SWE.

13.7 Sport/exercise type

Sport/exercise type was shown to have an affect upon seizure frequency, body control, and mental and physical well-being for the SWE. Although the results cannot be portrayed to be ‘true’ for every SWE, these results can be a good starting point to provide multiple beneficial sporting avenues for SWE.

Running and swimming were the most common exercise choices amongst the participants. Being seen as a moderate to vigorous activity, these choices in sport/exercise type meet the recommended intensity of exercise for PWE/SWE (Ablah et al., 2009). As medical and quantitative research has been seen within the area of physiological and psychological effects of exercise on PWE (Elliott et al., 2008), there has not been qualitative research examining the effect of sport type on a SWE. Therefore, these results can provide an initial glimpse into the effect of sport type/intensity level within psychosocial parameters for a SWE. One potential reason for these sports to have such a positive effect could be found in Arida, Scorza, and Cavaleiro (2010) which stated, “The increased attention and vigilance during physical activity could partially explain the reduced number of seizures in people with epilepsy” (p.77). This signals a confirmation of statements within these narratives where, for example, Gwen and Maya felt they would not have a seizure because they were focused during exercise. High-intensity exercise seemed to create an occurrence of seizures for these participants. This cannot be generalised for the population of SWE, but research has shown that intensity of exercise (e.g., moderate intensity) may be a key in allowing more frequent exercise for the SWE (Arida, Scorza, da Silva et al., 2010; Dubow & Kelly, 2003; Eriksen et al., 2002; Nakken, 1999; Sirven, 2009; Steinhoff et al., 2002).

The occurrence of seizure frequency linked with moderate exercise was not found within this thesis, however, there were some interesting hypotheses made by the participants along the way. Examining the effects of each sport/exercise more closely, the following will provide more reasoning for the benefits of these activities for the SWE.

The sport/exercise of running was seen to be efficient for maintaining health levels. It seemed to provide a state of relaxation, however, if “seizurey” feelings were present, running would rarely occur. Length and intensity was altered on any given day, and the participants reported running from anything between two miles to an hour. As time progressed and seizures were controlled, the participants would increase the time and occasionally ‘test’ their bodies by increasing in intensity as well. For example, this was seen in the form of trying to go faster on common running loops. However, when these increases in intensity occurred, common results were either a seizure or “seizurey” feelings. Gwen, Andrew, and Rose reported often realising when they had pushed themselves too much. Usually it would not be during, but after. Nakken (1999) reported symptoms of EIS in connection with exercise intensity, however, it did not seem that through the participants’ discussions on frequency of seizures in connection with intense exercise, that their seizures were EIS. As this was not physiological research, I am not confident stating that seizures were directly triggered by the SWE’s exercise routine. Reported by the participants, it only seemed that Andrew felt a direct connection with doing too much exercise, as he explained with seizures occurring after doing intensive exercise. This could be further monitored by Andrew and his neurologist, and could possibly create an answer to his physical limits and seizure triggers. Further

investigation would need to take place to find the connection between seizures and exercise intensity.

Swimming was the one sport that was used amongst all of the participants and showed beneficial physical and psychological results. Not only did it seem to result in achieving a state of relaxation, but it also heightened body control, provided a social outlet, and gave them a sense of normalcy. The choice of swimming as a popular exercise activity for the SWE was also found within Steinhoff et al. (1996). Although there were positives to swimming as a sport/ exercise for the participants, the constant neglect of disclosing their epilepsy to the lifeguard has drawn attention to exercise safety for SWE. Over the year, Gwen, Maya, Andrew, and Rose described that they felt safe enough to not tell the lifeguards. Although they acknowledged the dangers of a seizure occurring, the reasoning behind not telling a lifeguard was that sometimes, they just want to be ‘normal.’ This was linked to the hidden illness identity discussed previously and epilepsy’s stigmatic effect. Even in the situation of a seizure in the pool, as in Maya’s case, denial of safety measures were consistent amongst all the participants.

Personal reflection: *These discussions always troubled me as researcher and a SWE. I know the feeling of guilt that you are being ‘naughty’ to not tell the lifeguard. Yet, there is also the feeling of just wanting to have a nice swim, without feeling as though someone on the deck is panicking. Hearing each participant say these words made me realise this was definitely one topic that needs to be explored further.*

Although exercise is being reported to be a beneficial complementary therapy, it still has yet to be commonly suggested by many medical professionals as a benefit (Arida, Scorza, da Silva et al., 2010). These findings will hope to increase the reasoning behind viewing exercise as a beneficial complementary therapy for SWE/PWE.

Current research has shown a trend to investigate complementary exercise for PWE. Different physical activities, such as judo (Arida, Viera, & Scorza, 2010), karate (Conant et al., 2008), and yoga (Lundgren et al., 2008; Ramaratnam, 2001; Yardi, 2001), have been shown to provide relaxation as well as bodily control for PWE. Exploring this adaptation topic within the narratives, Rose and Gwen expressed similar sentiments regarding alternative exercises. Gwen taking up tai chi found it to create a sense of relaxation and bodily control, similar to what was found in Conant et al. (2008). Gwen and Rose found yoga to be an alternative exercise that was not physically demanding, but a de-stressor, which substantiate similar findings found in research (Lundgren et al., 2008; Ramaratnam, 2001; Yardi, 2001). As one of the main triggers for seizures was stress (Ramaratnam, 2001), alternative or complementary exercise could be a possible way for SWE to maintain or increase self-confidence, stay physically fit, and decrease the possibility of future seizures. With these findings, it is justified that alternative/complementary exercise should be further investigated. Influenced by other variables (e.g., emotional response, seizure frequency, sport type, etc.), next the topic of social support will be discussed as seen over the year.

13.8 Social support

Social support is a prevalent variable within research for PWE (Charyton et al., 2009; Elliott, Charyton, Sprangers, Lu, & Moore, 2011; McEwan et al., 2007), however this thesis provided the first insight into this variable within the context of exercise. Ranging from friends, spouses, parents, coaches, and doctors, each participant expressed both positive and negative aspects of a support network's recommendations/effect on their exercise habits. For example, Gwen expressed the continued support her husband provided as she desired to exercise, however, his ability to exercise consistently seemed to increase her desire and frustration in terms of exercise. Andrew received mixed messages regarding medical advice, and this seemed to have contributed to the roller coaster of emotional response. Maya expressed problems with her medical and familial support; over the year, the fear of being withheld from her sport seemed to stir up a defiant attitude within her. This defiant attitude was not eased by a support system who understood her epilepsy. It seemed that she felt quite alone regarding her frustrations with her end swimming goals and any possible bureaucratic limitations. Finally, Rose seemed to battle other's prejudices, enacted stigma, as well as their lack of education regarding epilepsy. Initially, she felt quite alone and I felt she was very relieved to express these emotions with me as she had not discussed such situations with anyone else. With each interview, I could see her getting things off her chest and really thinking about what made her exercise and what made her not. By the end of the year, she felt more comfortable in her own skin, and as a result was opening up to others about her epilepsy.

In regards to medical support, these narratives reveal conflicting medical advice for exercise. Research confirms that exercise should be encouraged, not discouraged for SWE (Arida et al., 2013; Dubow & Kelly, 2003; Nakken, 1999; Sirven, 2009). Although there is an abundance of research stating such advice, it was not shown to be provided across all SWE. For example, Andrew's advice from his neurologist to quit his exercise caused a strong negative emotional response. However, 3 months later, an epilepsy nurse encouraged him to exercise. As this caused a very different emotional response, it should be reviewed amongst medical professionals on proper advice for SWE. Also of note would be the potential psychological effects from disregarding the consequences of discontinuing exercise. This thesis hopes to draw attention to the miscommunication that may have been occurring between SWE and their medical providers.

Within each narrative, social support seemed to have a large part to play in not only sport/exercise choice and routine, but also stigma, coping success, and identity. These results show a commonality within current social support findings (Charyton et al., 2009; Elliott et al., 2011; Schachter, 2008; Sturm et al., 2002). Derived from these narratives, social support confirmed previous research suggesting that a perceived/felt stigmatic view of their epilepsy from others created a heightened lack of disclosure (Baker et al., 1999; Charyton et al., 2009; Schneider & Conrad, 1980; Troster, 1997). The lack of communication both ways was linked to this stigmatic feeling and negative emotional response (Baker, 2002; Schneider & Conrad, 1980; Troster, 1997). Also found were the increased feelings of self-efficacy and less depressive symptoms through positive social support influences in lifestyle management, including exercise (Charyton et al., 2009; Robinson et al., 2008).

Current research has not shown a specific interest in social support linked with exercising habits of SWE. This thesis provides an avenue to explore further this prospect, not only for those who feel the importance to exercise, yet also SWE who desire to maintain exercise habits. Schachter (2008) was one piece of literature where a social support network's feelings toward exercise were shown. This provided similar statements as described by the participants, yet through the social support's own words. Although there was a limited number of statements regarding exercise within Schachter (2008), it has shown social support to be an important topic, and that there is a desire for the social support's voice to be heard as well. The effect of social support upon a SWE's motivation, emotional response, and sport choice has a strong dependence on what reaction or encouragement their friends, family, and doctors have provided. It is desired that the importance of this is seen by other researchers and as a result, further research will be conducted.

13.9 Concluding thoughts

Upon discussion of the major themes that were discovered within the overall narratives, the one important aspect to focus on was the thematic thread that ran between each. Ranging from the psychological and physical benefits of exercise, non-disclosure of epilepsy, being frustrated over not maintaining exercise habits, and not wanting to be called 'epileptic' or disabled, all these were symbiotic and are evolved together over time. As shown, some variables increased and decreased through time, but some remained consistent and did not fade away. Future research to progress this thesis would explore the previous topics discussed and examine further how each could be a deciding factor regarding exercise. It is hoped that as a result of these narratives, SWE will be

able to see themselves or portions of themselves and learn. Ranging from trying different sports/exercise type to being aware that adaptation is beneficial to exercise maintenance, these narratives have provided valuable insight into ways to exercise with epilepsy.

As reflection was a constant and important aspect of this research, the following will present my reflections on the research process as well as how I have been affected by performing this research.

13.10 Self-reflection

Throughout this research, reflection was a method that was utilised to become more aware of the participants' stories as well as my own strength and weaknesses as a researcher. Not only did reflection allow self-awareness of my own issues with exercising with epilepsy, but also how I have become more accepting of my sporting life with epilepsy. I feel stronger within my own identity and body because of this research process.

Reflection journal- 16/11/11: I all of a sudden realised that I have not written down a theme that is coming up with everyone: ME. The effect of talking to someone else with epilepsy, my asking questions, and just letting them talk. A lot have said because I am so open, they realised there's nothing to be ashamed of. Also, them even joining Epilepsy Action activities, re-thinking exercise activity, etc. Is this a good or bad? I guess any talking about personal issues will have an effect. But how much change have I made?

Although I will not know how much affect I had, I will acknowledge that there was some influence. I do not believe this influence was negative. Through

acknowledging this affect, I am allowing myself to be open for criticism. However, I believe that it is through this acknowledgement that I draw attention to the positive and negatives of being a SWE interviewing and analysing fellow SWE. First, the participants may have felt more comfortable with me as a fellow SWE, thus allowing them to discuss private matters more openly. Several times being told by the participants that “I’ve not told that to anyone,” seemed to confirm this. Their desire to hear my side as well created trust between us as fellow SWE as well as participant/researcher. Second, some questions were derived from personal experiences as a SWE, questions that may not have been asked had I not been through a similar experience. I felt my closeness to the subject matter allowed me to have an insider’s view, and investigate issues that I wanted clarifying and shared as they had yet to be discussed within literature. Third, I felt that as a SWE, I had a strong desire to get these stories within the public domain in order to create an avenue to help other SWE cope. This being said, there were also negative aspects of being a SWE. First, I was emotionally affected at times to their stories as I had been in similar situations. It was a challenge to stay unmoved when phrases and feelings that I had never discussed with anyone were being told to me. However, proper strategies to continue as researcher were put into place. Discussed earlier within the methods chapter, I felt that allowing myself to talk to an outside individual (e.g., supervisor) aided this feeling of wanting to discuss my own issues with the participants. Second, I was worried that by being a SWE, there was the possibility that assumption that “I knew” was created within the participants. When I felt that there was a feeling of assumption from the participants, I made sure to continue asking questions to allow them to clarify. Although I will not be sure if this was

completely successful, I did feel that this research benefited from my closeness to the subject matter and the pros outweighed the cons. Bringing to light the stories of these SWE, the research and epilepsy community will finally hear the stories of those previously hidden.

Over the year of interviews, I became intrigued about what could happen next for each participant. These people were not only participants that I studied, but I had a genuine interest in their well-being and experiences. Feeling more at ease with the research process and confident in myself as interviewer/researcher, I felt the interviews gained strength as time went on. This may have been shown by becoming more confident to press for clarity, for example, asking questions that seem like they might upset them, etc. Growing as a researcher as time went on, I also have benefited in terms of my own exercising life and acknowledgment of personal limitations and how to adapt.

As the thematic and narrative contributions to literature have been discussed, the next section will draw attention to the importance of using this type of narrative analysis for this research.

13.11 The importance of narrative research

Exploring the SWE's experience over time, it seemed fitting to use a narrative analysis to portray their story. Portraying the 'narratives as illness' and 'illness as narratives' (Hyden, 1997), through these narratives, the SWE can now have a voice within research. In upholding the levels of narrative analysis (Murray, 2000), this thesis portrayed the differing and integration of levels within the narrative outputs. First, in the

use of the personal level, identity shifts/stability were demonstrated over time; second, through the interpersonal and positional levels, the effect I, as researcher, was reflected upon and discussed within interviews and narrative formation; and finally, through the ideological level, societal representations of a SWE can be discussed and debated as this research has presented four different SWE that have shared their experiences and invite future discussion. Through integrating these levels throughout the narrative analysis process, a richer narrative was formed, portraying the complexity of the SWE's exercise experiences.

In aiming to uphold the ideals behind postmodernism and poststructuralism, I examined different ways to analyse and depict these individuals, however, it is understood that others may see a different side to what I saw. Different themes may be exposed to someone who is more separate from the research, even different structures of narratives. However, as reflection is a part of poststructuralist ideals (Richardson, 2000), it seemed fitting to acknowledge that through this narrative research, new ways of investigating SWE have emerged. Being immersed within this research and using language to portray an experience, narrative analysis has shown to be a beneficial method of representing the lived experience. Producing language (e.g., seizure, vicious cycle, etc.) that has yet to be shown within research, poststructuralism seemed to present itself as relevant to narrative analysis. The narrative types and themes shifted over time, thus re-stating the importance of the unfixed, not stable self (Richardson, 2000). Although an ideal of postmodernism is that “no method has a privileged status” (Richardson, 2000, p.8), by investigating SWE using this method of narrative analysis, it

is hoped that more conversation and opportunity to explore the lived experience can now be shown.

13.12 Concluding thoughts

Furthering present day literature, each story has allowed a glimpse into the life of a SWE. Upon reading these stories, it is hoped that an interest into the SWE has been inspired and as a result, more research will allow further insight into the exercise experiences of a SWE.

14.0 Conclusion

In providing the lived experience for the SWE, this research has allowed the SWE's narrative type and prevalent themes to be depicted within current literature. As a result, SWE will now be able to realise that they are not alone and that their voice is finally represented. Although these narratives cannot be generalized, for every SWE is not the same, this research can now be moved forward to provide other SWE with a voice. In this chapter, the impact of the previous findings will be discussed, followed by future research that can be derived from these results.

14.1 Significance of these results to present-day research

“Exercise...empowers me.”-Andrew

“I want to be the first person who has epilepsy that will swim the Channel!”- Maya

“Before I saw it as beneficial, whereas now I’m weighing the benefits against the possible consequences.”-Rose

“I think... the frustration, the absolute frustration that your epilepsy has control over you, deciding for you, the level of exercise you do. Rather than you being able to make that decision.”-Gwen

These statements represent an element of each participant's story. Each participant had a different story to tell. Although thematic results were discussed in the previous chapter, next a summary of the research will present how this research will impact the epilepsy and medical community.

Aiming to present first-hand insight into topics pertinent within previous quantitative literature as well as investigate topics previously unseen, this research presented the emotional impact of exercising with epilepsy over time. Time played the major role within these narratives. Through the use of time, the narratives presented individuals whose daily life changes moment to moment, and who are trying to achieve a successful exercise life with epilepsy. Exhibiting trial and error as well as coping mechanisms to have a steady psychological state, these participants have shown how epilepsy is a continual disorder that does not seem to get considerably easier to live with as time goes on. Although for some of the participants, exercise routine and acceptance became more steady, increased seizures or other variables (e.g., medication, social support, identity, etc.) created an on-going cycle or shift over time. Not seen before within research, it is important to acknowledge the affect that time has upon the SWE's exercise story. From here, further research exploring this cycle and how to best break it should be performed to encourage SWE to exercise.

Second, upon exploring the topic of identity for the SWE, the concept of athletic identity has shown to be a driving force to maintain exercise habits as well as create a heightened negative emotional response when exercise was prevented. This is important to draw attention to as future medical advice can be cautioned according to a SWE's athletic identity. Also, the topic of hidden disorder/epilepsy and disabled identity linked the theme of stigma and social support for the SWE. Deriving results from this research, it would be advisable to educate others about epilepsy, thus reducing stigmatic effect. By presenting this research to SWE, it is hoped that acknowledgement of their own

issues within another's story will help them cope with the outcomes of their epilepsy upon their exercise life.

Third, connected to identity and stigma, the concept of the healthy versus ill body also appeared to influence the SWE's exercise routine as well as his/her personal view as disabled/non-disabled. Denying an ill body or submitting to one's ill body created both positive and negative emotional reactions. These reactions were also affected by multiple variables (i.e., social support, athletic identity, seizure frequency, etc.), and changed over time with an evolving view of his/her body. Creating a new area for exploration within future research, it would be of interest to explore further such findings and see similarities or dissimilarities in comparisons with epilepsy and other illnesses/disorders, or even, serious injury.

Fourth, exercise type has allowed valuable insight into possible sport choices for SWE. Not in a clinical setting, these narratives derived valuable information on everyday sport choices and the psychological and physiological effect of the differing types. It also drew attention to the stigmatic effect and safety concerns with exercising with epilepsy. In the future, non-disclosure to safety personnel may be heightened against in order to increase the feelings that SWE should disclose their epilepsy, for their own well-being.

Fifth, in regards to social support and medical guidance on exercise, I was taken aback by the conflicting advice provided by medical professionals to the participants. There is a plethora of information to provide benefits to exercise, yet there are not enough specialists within exercise and epilepsy. With this research, an area of expertise

has been developed, leading to furthering research within this area and enabling the provision of more appropriate advice and guidance to medical professionals and families and friends of SWE.

Finally, derived from these narratives, a new narrative type was presented, drawing attention to the impact of narratives for the SWE. The vicious cycle was presented as a narrative type not yet seen within current literature. Not only was a new narrative type found, but the experiences of narrative types changing over time has yet to be found within current literature for the SWE. Differing in form from other chronic illnesses/disorders, this allowed further insight into the struggles of exercising with epilepsy and the various elements that allow someone to successfully or unsuccessfully exercise with epilepsy. In presenting possible narrative types of the SWE, this research has not only provided access to previous undisclosed topics pertinent to the SWE, but allowed access for fellow SWE to feel as their story is now being heard. Following acknowledgment of the significance of this research to the medical, sport, and epilepsy community, the limitations of this research will be discussed to acknowledge how this research could be improved upon.

14.2 Limitations of the research

Through the course of performing this research, limitations of this research process have been noted. There were three limitations that were apparent at the end of this research journey. First, the absence of more than one male's experience of exercising with epilepsy. Although I felt fortunate to present Andrew's story, it would have also been beneficial to have more than one male as any differences between male

and female perspectives would have been shown more clearly. Second, the age range between the participants was very similar. As the participants ranged from early 20s to their late 30s, I felt this portrayed a limited variance of people with epilepsy. It would have been interesting to capture older SWE as well to present a more holistic view of the SWE. However, both these limitations are present because of the availability of participants and a limited time scale. Finally, the third limitation was the inability to present the impact of diary writing for the SWE. Although not a main aim of this research, I was interested to see if diary writing had an impact as shown within other research (Dornelas, 2008). However, I felt that I did not set strict enough guidelines, nor asked for the diaries at the end of each participant's interviews, thus foregoing this as a data element. Using these diaries as an exploration tool within this narrative research, I believe that in the future, it would be of interest to examine whether diaries do have a positive or negative impact on the psychosocial impact for the SWE. In presenting these limitations, it is desired that future research can benefit from viewing these limitations and progressing the research method further. Next, recommendations for future research for the SWE will be discussed.

14.3 Future research

To further the results of this thesis, the next section will discuss potential future research that can be derived from these results. Although there can be a variance of research derived from these exploratory narratives, I have chosen four topics that are absent within present research and would benefit from further study. These were chosen as they seemed most pertinent in regards to SWE's identity formation and coping with/or lack thereof in regards to exercise.

First, the investigation of the emotional response over time for the SWE would benefit from further in-depth study. Acknowledging the affect time has on the SWE has opened the door for more research involving the temporal concept and its impact upon the SWE's emotional response. Previous exercise research with PWE has not shown such a link with time, and it is desired that further research will look into the temporal effect on the exercise experience for the SWE. Using IPA and investigating a larger number of participants, future researchers could investigate the common link between time and emotional response, as well as thematic connections. Including the use of diaries as a research tool, this PhD research aimed to examine if diary use could be a beneficial outlet for the emotional reactions of exercising with epilepsy. The feeling of "getting it out" by the participants was one avenue that requires more investigation as similar results have been shown in other health and exercise research (Allen-Collinson, 2005; Dornelas, 2008; Smith, 1999). Using diaries as one of the research tools in this future qualitative research could provide a clearer picture of the benefits of diary use for the SWE.

Second, within this thesis, identity was a topic that sparked insight into the impact of exercise or lack thereof for the SWE. The narratives created results of acceptance/denial of bodily limitations as a result of athletic identity. In order to explore this concept more thoroughly, it would be of interest to examine this topic within future research. Within exercise and epilepsy literature, the topic of hidden disorder has also yet to be examined in-depth. Therefore, further discussion on healthy versus ill body could be explored to provide a more in-depth look at how best to help SWE cope with the invisibility of their illness and the impact it has upon their exercise

routine and self-identity concept. Using IPA or discourse analysis, it would be of interest to explore the concept of language in the SWE's identity concept. Coping mechanisms to accept one's body and exercise healthfully would be a beneficial outcome of such research.

Third, a narrative look over time into the support network of SWE would be of interest to the SWE community. From the results found within this thesis, it is shown that, over time, a social support network can have both a positive and negative effect on the exercise experiences of SWE. Furthering this research, it would be of interest to present the stories of the SWE's support system. Discovering differences between participants in medical advice over time as well as across the individuals, it would also be interesting to explore the narratives of medical professionals (i.e., neurologists, nurses, etc.) to examine the differences between research outputs and medical advice. This may lead to improved medical advice and a stronger push towards positive motivation regarding exercise as complementary therapy. Furthermore, investigating the narratives of the SWE's support system, research would be able to present what parents, partners, and friends feel in regards to exercise and the SWE.

Finally, using a grounded theory approach, it would be beneficial to further investigate sport/exercise type and the differences and benefits of different types for SWE. This would add to current findings of safe and beneficial exercise types of which to choose (Arida et al., 2008; Eriksen et al., 2002; Conant et al., 2008; Heise et al., 2002; Yardi, 2001). Included in these future findings should be a comparison of exercise intensity and seizure frequency regarding benefits and recommendations to exercise. As

a result of such research, future guidelines for exercise safety and benefits could be outlined for the SWE and their support system.

The next section will discuss how this research, through acknowledging another's story, has impacted my life as a SWE.

14.4 Impact of listening to a SWE's story on an SWE

Performing this research, I have awoken to a new comfort level within myself as a SWE. Previously reacting similarly to the participants in the lack of disclosure and frustration of not exercising as others are able, I have learned that this does not need to be the case. Through my discussions with my supervisors to hearing my participants tell their story, I have seen the outsider's point of view. I have come to acknowledge that although I may have some physical limitations, I do not need to give up on myself. Yes, it is not my ideal way of living; however, I can have a very good life and include exercise within it! Upon completing analysis on the last narrative, I had begun to run again. I am not running with a goal of competing, instead, running now is to satisfy my desire to maintain a healthy physical body through consistent exercise. When I achieved four days of exercise in one week, I was ecstatic!! Then I had two weeks off because of multiple seizures on multiple days. These seizures set me back emotionally, however, upon beginning my routine again I resolved myself to not give in to my frustration and anger. I have begun to listen to my body, not fear it. This balance was hard to achieve, and I see it as a daily effort. This daily effort was seen within these narratives of the SWE, and it should not be ignored. I have grown as a SWE and am very proud to have done this research. I believe these stories will cause a change in SWE's point of view on

exercise as now, in reading these stories, they may no longer feel alone in their daily efforts to exercise. This excites me greatly and I am eager to continue my personal growth as a SWE as well as further this research to create an increased knowledge within society and for SWE.

14.5 Concluding thoughts

One aim of creating the narratives in their current state was to create a sense of a SWE in front of you talking, rather than just words on a page. These narratives have now contributed a substantive amount of new information to the public and SWE are no longer alone in their thoughts and feelings.

As seen by reviewing each narrative type and thematic elements, a SWE's narrative is complex. I was intrigued by these results and excited to present the research as these topics discussed have not been seen within present day research. In producing this research, it is my desire for you, the reader, to have further insight into the SWE's experiences and as an end result, spur future research within exercise and epilepsy.

Appendix 1- Consent and Debriefing forms



PARTICIPANT CONSENT FORM

Understanding the psychosocial impact of exercising with epilepsy:

A narrative analysis

Brief Description of Research Project:

The main aim of this research is to examine one year in the life of sportspeople diagnosed with epilepsy. Following diagnosis of epilepsy, this research will track 5-10 sportspeople of different ages, sport type, seizure type, and sport level for one year capturing the experience of living with epilepsy and its affect on exercise. Questions will be asked around the topics of sporting life and epilepsy, how epilepsy has affected your ability to exercise, your social support systems, how you identity yourself, and what it is like to live with epilepsy. The research will consist of four interviews spread over the course of one year, one every three months. Interviews will last approximately one hour or more and, with written and verbal permission, will be audio recorded. Diaries will also be provided to track one's feelings and thoughts concerning exercising with epilepsy.

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Consent Statement:

I agree to take part in this research, and am aware that I am free to withdraw at any point. I understand that the topics discussed can be of a sensitive nature and I may become upset and distressed. I understand that the information I provide will be treated in confidence by the researcher and that my identity will be protected in the publication of any findings. I understand that this is a research study, and the main researcher is not a trained counsellor. If I do want to be referred to a counsellor and/or support groups, I understand that the main researcher will supply me with referral services. I understand that if I give the researcher cause to think that I may be of harm to myself or others, confidentiality will be broken so that proper services may be obtained.

Name Date

Signature

Please note: if you have a concern about any aspect of your participation or any other queries please raise this with the main researcher. However if you would like to contact an independent party please contact the Dean of School (or if the researcher is a student you can also contact the Director of Studies.)

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PARTICIPANT DIARY CONSENT FORM

Understanding the psychosocial impact of exercising with epilepsy:

A narrative analysis

Consent Statement:

I agree to allow the use of my diary for data collection. I understand that in doing this, I will be allowing personal, sensitive material to be used within my analysis. I understand that only the main researcher will be allowed to read my raw diary and confidentiality will be kept through the use of pseudonyms. I also understand that by signing below I acknowledge that my diary may be used within data collection to be used for publication in research articles, magazines, or presentations. I have been told that I am free to withdraw at any point, and I do not have to show my diary to the main researcher if I do not wish.

Name: _____ Signature _____

Date _____

Please note: if you have a concern about any aspect of your participation or any other queries please raise this with the main researcher. However if you would like to contact an independent party please contact the Dean of School (or if the researcher is a student you can also contact the Director of Studies.)

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Information Sheet

Understanding the psychosocial impact of exercising with epilepsy: A narrative analysis

This is a PhD study capturing one year in the lives of people who exercise with epilepsy. Although epilepsy and exercise is becoming a well-researched topic, the domain of research is quantitative, or through the use of questionnaires. There is, at present, no research concerning the experience of those who are now persons with epilepsy and are adapting to their new sporting life. By examining the diagnosis period as well as the sports variable on people with epilepsy, this research will be able to provide first-hand experience of adapting to a new life with epilepsy and the acknowledgement of what that means to one's new body. This research will also provide further growth within the field of epilepsy and exercise.

There will be four interviews in total, spanning over the course of a year. The first interview will be conducted as soon as recruited, in a location comfortable for you. The next three interviews will be three months apart. The interviews will follow an unstructured format, although I will be asking questions following themes around topics of living with epilepsy, your sporting life and routine with epilepsy, identity, and the descriptions of your social support system and its impact on your sporting life with epilepsy.

Individual diaries will be given to you to capture your thoughts concerning your sporting experience. Diaries will be used as a memory-boosting mechanism for interviews, as you will be asked to capture any activity that causes you to reflect on your sporting life. It can also serve as a way to write down any thoughts that you may feel too personal to tell anyone or do not have anyone to tell. The interviews will be approximately an hour or more, depending on how comfortable you are in continuing with the conversation. Each interview will be audio-recorded for data collection. You have the right to refuse to audio-record the interview and can terminate the interview or leave the research process without any repercussions at any time through the use of the pseudonym provided for you on the debriefing form. Confidentiality will be secured through the use of this provided pseudonym. Although you may withdraw from the research process, data already provided may still be used and published for research purposes, however your identity will still be preserved through the use of a pseudonym.

Following the end of the research period, I will supply a printed copy of your narrative for you to check to see if your statements are correct as you remember. I will

not keep or read your diaries unless you provide written permission. Re-reading the interviews may cause emotional distress and may make you more sensitive to the issues that are discussed throughout the interviews. If you would like any outside psychological support, Epilepsy Action has available support groups within multiple regions as well as the UK Epilepsy helpline which provides emotional, informational, and listening support. If additional support is needed, references to chartered psychologists registered with the British Psychological Society can be provided.

Please note: if you have a concern about any aspect of your participation or any other queries please raise this with the main researcher. However if you would like to contact an independent party please contact the Dean of School (or if the researcher is a student you can also contact the Director of Studies.)

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Participant Debrief:

Understanding the psychosocial impact of exercising with epilepsy: A narrative analysis

Thank you for participating in this research on epilepsy and sports. I greatly appreciate your continuous contribution in raising awareness of epilepsy. This study was aimed to explore the life of a sportsperson with epilepsy over the course of a year through the use of interviews and diary writing.

Please read the following:

- The interview was conducted in an ethical and professional manner paying close attention to the sensitivity I may feel in regards to issues raised over the course of the interview.
- I am aware that I do not have to submit my diary to the researcher unless I personally feel comfortable to do so.
- The narratives will be made available to me, to check for feedback and accuracy.
- I was allowed to end the interview at any time throughout the course of the interview, and was made aware of that prior to start of the interview
- I have the right to withdraw from the research process at any time without any repercussions
- I have been assured that my anonymity will be secure through the use of pseudonyms

If you feel the need for any emotional support as a result of the issues arisen from participation in these interviews, Epilepsy Action provides support groups within the London area. There is also a UK Epilepsy Helpline which you can call if you feel as if you need someone to discuss such issues. You can reach this helpline at 0194601400. If you would like any further listening or emotional support, through your GP you will be able to be referred to a chartered psychologist.

Please note: if you have a concern about any aspect of your participation or any other queries please raise this with the main researcher. However if you would like to contact an independent party please contact the Dean of School (or if the researcher is a student you can also contact the Director of Studies.)

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Appendix 2- Interview Guide

Example of Interview 1:

Exercising Describe your experience of exercising with epilepsy?

How do you feel when you are exercising?

Have you ever faced any barriers?

Who/ what helps you the most/hinders

-How long till you exercise again? What goes through your mind to stop you from exercising?

Have you found anything to prevent seizures/help your recovery?

Have you adapted to living/ exercising with seizures? How? What ways

Does your medication ever affect your exercising? How?

What do your fam/friends think about your exercising?

Background Tell me about yourself?

-job

-family life, friends

-what do you do for exercise?

-Seizure description and type

Meds?

Describe a typical week's routine?-work, sports, lifestyle

Can you describe what it's like to have your type of seizures? Aware, not aware?

How do you feel prior/after a seizure?-emotionally/physically, recovery

Do you know anyone else with epilepsy?

What does a normal day feel like?

What is it like for you to have epilepsy?

Diagnosis How did it feel when you were diagnosed?

Do you feel different now?

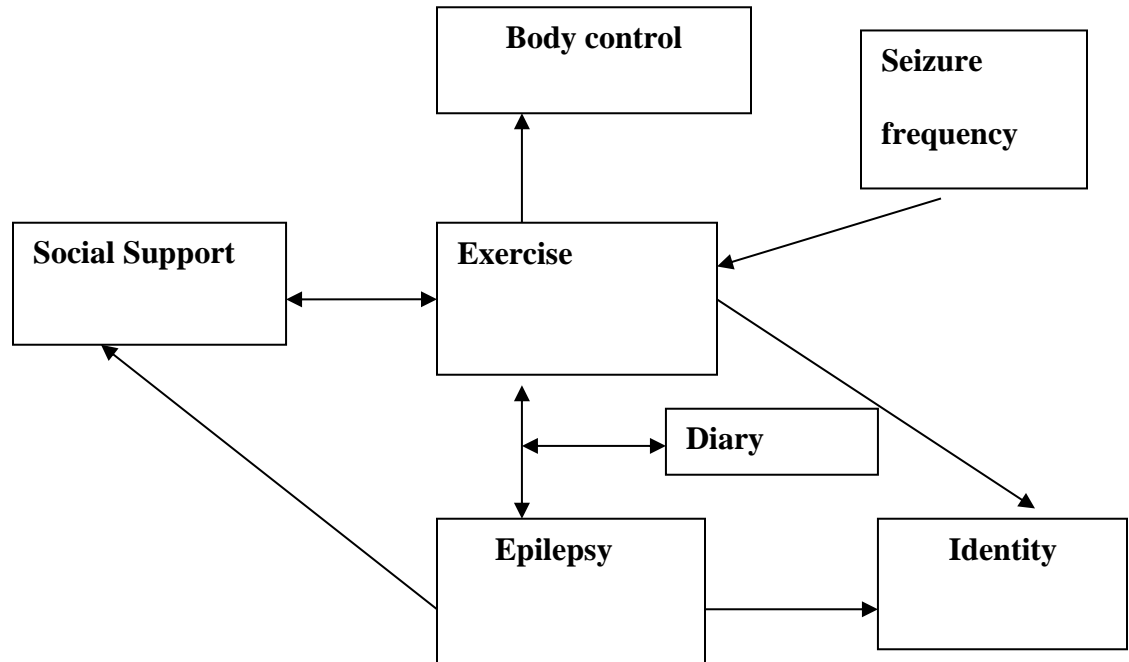
Social Support Do you ever wonder what others think if they see you having a seizure? Why or why not?

Do you feel epilepsy has made an impact on your friends/family?-how, what makes you say that?

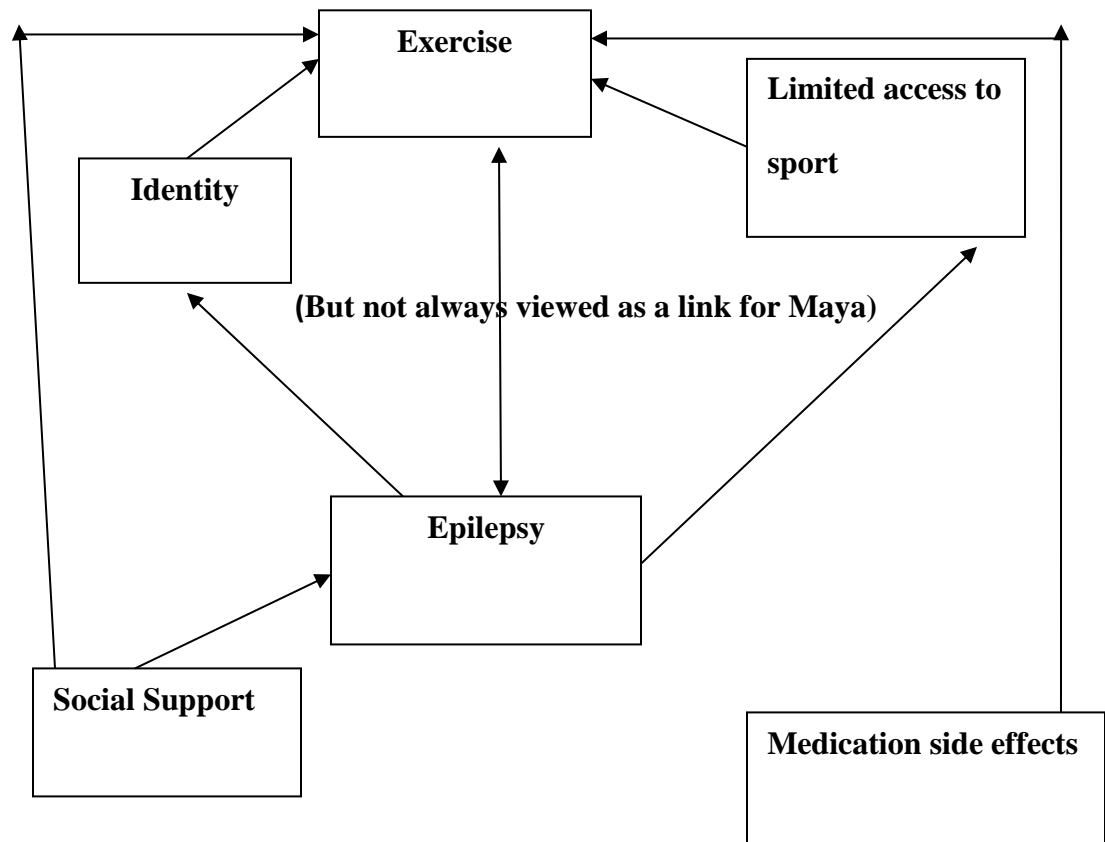
Do you see your epilepsy as a disability? What makes you say that?

Appendix 3-Mind Maps

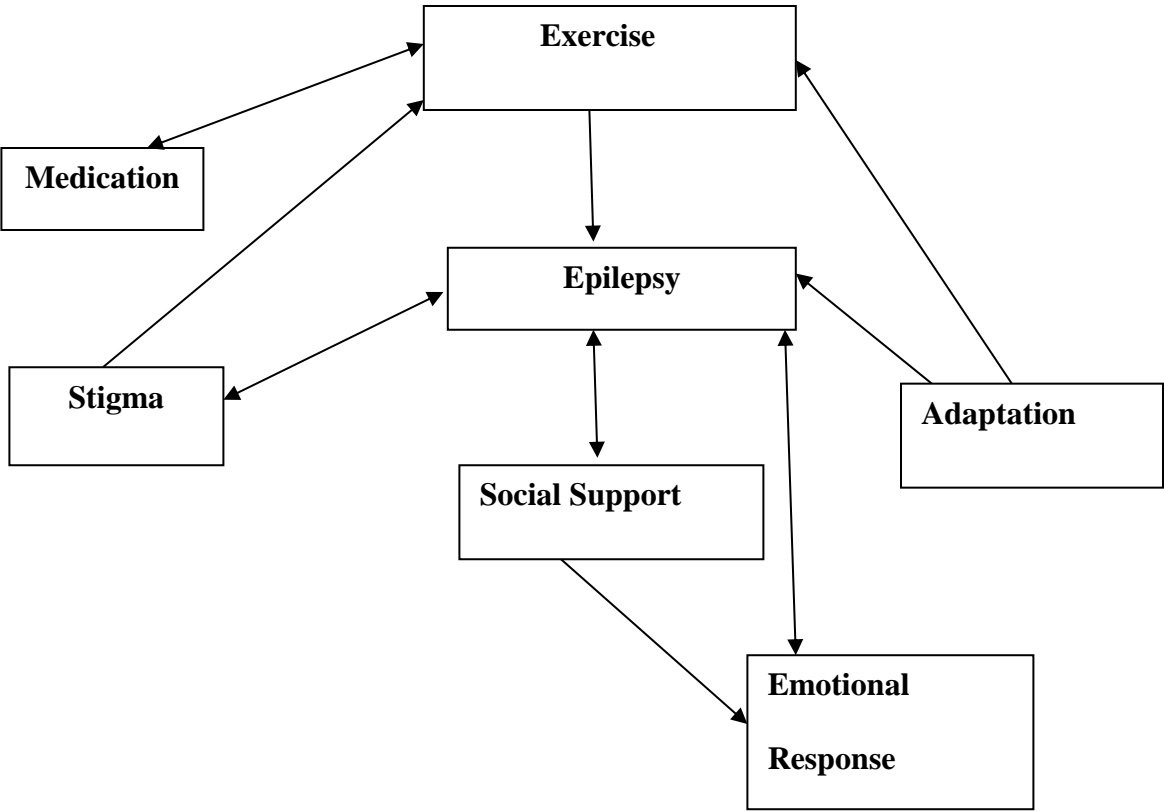
Gwen Mind Map-Narrative two



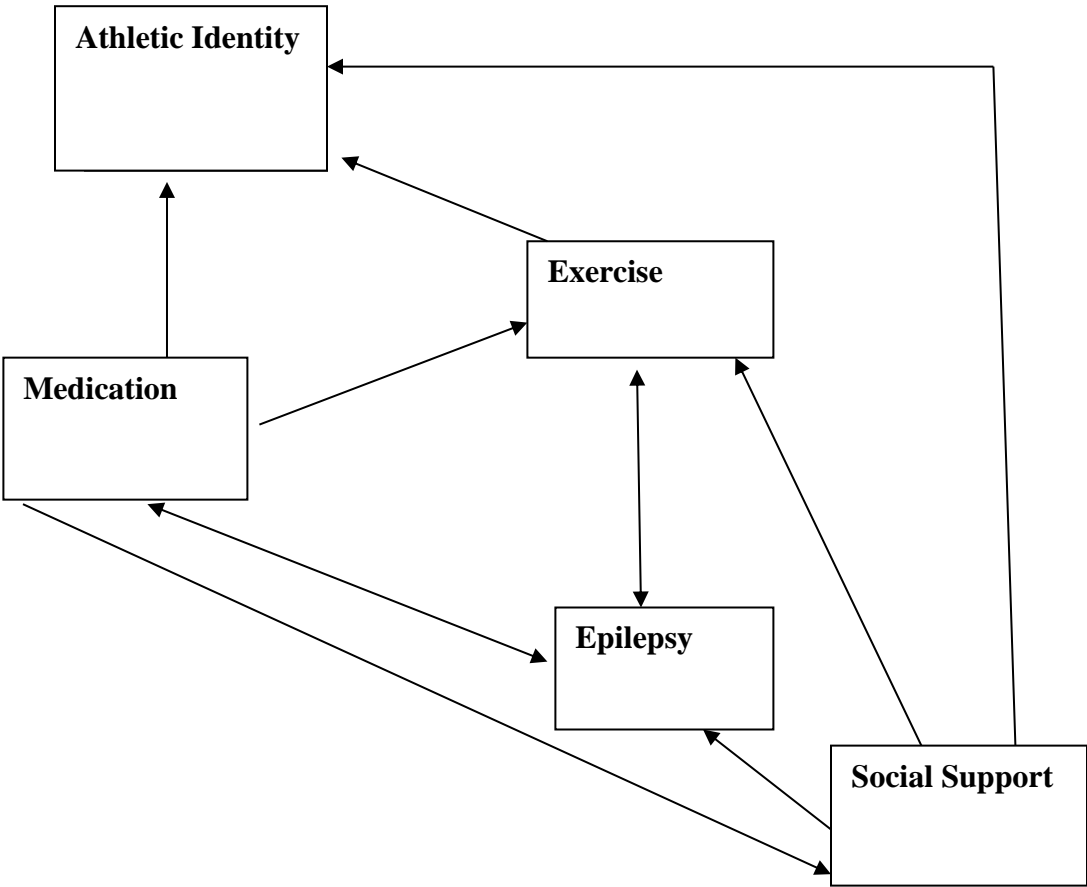
Maya Mind Map- Narrative two



Rose Mind Map- Narrative two



Andrew Mind Map- Narrative two



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